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ABSTRACT

Ten papers from a 1978 lecture series on employment, civil rights, education, social aspects, and recreation and leisure for disabled persons are presented. It is explained that as disabled persons, the lecturers presented role models to the students at the Regional Education Program for Handicapped College Students at Teachers College, Columbia. The following papers are included: "Handicap and Disability" (J. Heuzann); "Attitudes Toward the Disabled" (H. Yuker); "Liberal Education for the Handicapped" (R. Russell); "Education in Dentistry and the Health Professions" (M. Chanin); "Handicapping America: Barriers to Disabled People" (F. Bowe); "Civil Rights Aspects of Disability" (C. Brewer); "Concerning Employment of the Disabled" (J. Gavin); "The Provision of Social Services: A Dilemma for Our Times" (G. McMurray); "Athletics" (M. Soulek); and "Sculpture" (M. Naranjo). Summaries of panel discussions follow each presentation. (CL)

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Disability: Our Challenge

A Distinguished Lecturer Series,
sponsored by the Project for
Handicapped College Students*
Teachers College, Columbia University
New York, New York 10027

John P. Hourihan
Editor

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Preface

In the spring of 1978 a Distinguished Lecturer Series was presented in the New Jersey-New York metropolitan area. The Series was but one activity in the Regional Education Program for Handicapped College Students based at Teachers College, Columbia University. (This Program has come to be known as the Project for Handicapped College Students.) The Project is a resource center serving disabled students and their colleges within the area.

The purpose of the Series was to have authorities knowledgeable of the problems of disability lecture on topics of vital interest to the students served by the Project. Employment, Civil Rights, Education, Social Aspects, and Recreation and Leisure were the topics explored in the Series. As disabled persons the lecturers themselves presented role models to the students. They also presented to administrators and faculty dramatic examples of what their students could achieve.

The ten lecturers were held at five of the colleges associated with the Project–Ramapo College, Union College; New Jersey; Teachers College, Columbia University, Bank Street College of Education and Marymount Manhattan College; New York.

This publication presents all of the lectures in the Series and an introduction by the Project Director which places the Series within the context of the Project's objectives.

March 1979 John P. Hourihan

Acknowledgements

We are indebted to all those who participated in the Series—the speakers, the students, the faculties and administrators of the colleges and universities associated with the Project. Their support and enthusiasm for the basic concepts of the Series were the main factors for making it such a success.

Our deepest gratitude goes to Professor Herbert Rusalem, the Project's first Director, and Professor Frances Partridge Connor, Chairperson of the Department of Special Education and Principal Investigator for the Project. It was their genius that gave birth to the concepts upon which the Project is based.

The colleges and universities associated with the Project must be singled out for their expenditure of time and energy, not to mention funds, in order to enable the disabled to participate.

Not enough praise can be given to the enlightened Congressmen who passed legislation which not only made funding possible but also stated America's faith in the abilities of disabled people. Praise must be given, as well, to the United States Office of Education in the Department of Health, Education and Welfare for all that it has done for handicapped individuals. In this Office Dr. Edward Martin, Deputy Commissioner of Education, has attracted to the Bureau of Education for the Handicapped, professionals whose dedication and commitment is an inspiration. Among these is Melvin Ledson, Coordinator for Regional Education Programs. We are grateful to him for his invaluable assistance to our staff in advising the Project of which the Distinguished Lecturer Series is but a small part.

The Project staff planned the Series and this book is the result of a team approach. It was largely the talents and professional expertise of Frances V. Dillon, Project Assistant, that made this book a reality. Special thanks go to Diane Woods, Leonard Huber, and Carolyn Scott for their organizational work.

Special thanks are also due to Joyce Confer, Nada Clyne, Kathy Stuart-Harvey, Jane Johns, Abby Koota, Karen Luxton, Richard Mahler, Lorna McIntyre, and Lynn Fiske Watts for their continuing involvement in the preparation of this book.

Without the support of the Advisory Board members, Evelyn Dolan, John H. Fischer, Bette Knapp, Donald St. John-Parsons, and Rashida Yahya, it would have been impossible to offer the Series to students.

Every effort has been made by our editors, Evelyn Katrak and Carol Anderson, to preserve the integrity of the contributions of the lecturers and the panelists. Our heartfelt thanks to everyone who participated in making the Series live on in this book.

I. Introduction

The Spirit
Michael Naranjo

Our Challenge

John P. Hourihan

Throughout the history of mankind, persecution and prejudice have taken many forms–detention, denial of rights, discrimination, death–to name a few. Those who suffer these outrages may succumb and, if not die, experience a living death, or they may believe in themselves and the cause for which they strive, persisting even in adversity to find within themselves the stuff that leaders are made of.

This faith in one's self was seen in Ireland in the last century where, as the story goes, during the Irish disorders nine men were captured and convicted of treason against the Queen of England. All were sentenced to death: Charles Duffy, Thomas Meagher, Terrence McManus, Patrick Donahue, Richard O'Gorman, Morris Lyene, Thomas D'Arcy, and John Mitchell. Before passing sentence, Her Majesty's magistrate gave the condemned men an opportunity to make a statement–a fatal mistake considering that the prisoners were Irish. Thomas Meagher became the spokesman for all.

"My Lord," he said, "this is our first offense but not our last. If you'll be easy with us this once, we promise on our word as gentlemen to try to do better the next time. And next time–to be sure–we won't be fools to get caught." This so outraged the judge that he sentenced them not only to be hanged but to be drawn and quartered. Word of the unjust sentence spread around the civilized world. Passionate protest from other lands influenced Queen Victoria so that she commuted the sentence to exile for life in far off, wild Australia.

Twenty-six years after these events, word reached the Queen that Charles Duffy, who had just been elected Prime Minister of Australia, was the same man who had been shipped there in exile. An investigation of the whereabouts of the other men was ordered by the Queen. The following facts were uncovered: Thomas Meagher had become the Governor of Montana: Terrence McManus and Patrick Donahue were generals in th United States Army: Richard O'Gorman had been appointed the Governor General of Newfoundland: Morris Lyene had been Attorney General of Australia and was succeeded by Michael Ireland: Thomas McGee became Minister of Agriculture in Canada; and John Mitchell was a prominent New York politician.

This story dramatically illustrates the power of that drive within the human spirit which overcomes persecution and prejudice in order to make a contribution to the world. It is being reenacted even today in America. Disabled citizens, although they have been the object of discrimination for centuries, are proving that they have an important contribution to make. Many have entered the business world, the arts, and the professions, and have become successful.

Success for many of the disabled in our land has been the result of good education. The struggling Americans of the eighteenth century had little time for pondering the potential of the disabled as productive citizens and so did little to educate them. In the nineteenth century the tendency was to seclude them in asylums in rural areas where they would not prick the conscience of an "enlightened" people. The latter half of the nineteenth century saw the dawning of a new attitude to the education of the handicapped. Gallaudet College was chartered by Abraham Lincoln as the first college in the world for the deaf. Several of the colleges and universities whose students were nondisabled began to admit the disabled. The conferring of a Bachelor's degree on Helen Keller by Radcliff College was the sun that pushed back the dark night facing so many intelligent and competent disabled students. Their greatest handicap at this time was the fact that colleges and universities were not ready to accept them and that admissions officers were more concerned with their disability than with their abilities.

After World War II, the enrollment of disabled students increased noticeably. It is believed that this phenomenon was the result of several factors: changing social attitudes toward such students, the expansion of vocational rehabilitation programs, the improvement and increase of special education programs in private and public schools, and the adoption by business and industry of new perceptions of the productivity of disabled persons.

The second half of the twentieth century witnessed major changes in American higher education which in the long run were to benefit the disabled. Until this time only a small portion of the general population attended college and the few disabled persons who were enrolled were truly superior students. Such students, being few in number, did not require specialized programs nor did their disabilities necessitate, as a rule, architectural modification of the campus. This situation was the result of careful screening by college admissions officers and produced disabled graduates who not only compiled an outstanding record of achievement but who were also integrated into the routine of college life without any great inconvenience to the institution.

During the last decade open-enrollment policies and changes in entrance requirements made it possible for disabled youth, previously denied admission, to enter college. Administrators and faculties then had to cope with the increasing numbers of disabled students and required assistance from professionals who understood not only the problems particular to such students but the difficulties of the institution in meeting their needs.

In 1975, before the regulations relative to Section 504 of the Rehabilitation Act of 1973 became a burning issue, Professor Frances Partridge Connor and Professor Herbert Rusalem of Teachers College, Columbia University proposed that the United States Office of Education establish a regional center that would assist colleges and universities in the New Jersey-New York metropolitan area in planning for the delivery of supportive services to their physically disabled college students. The proposal was based on the conviction that environmental adjustment and specialized counseling could help large numbers of these students to meet college requirements for matriculation. The project was approved in 1976 by the Bureau for Education of the Handicapped in the United States Office of Education and will terminate in 1980. Its objectives are five-fold:

1. To provide severely disabled college students with a service program that will enable them to maintain themselves at an acceptable functioning level.
2. To assist students with alternate plans when it is clear that continued college attendance is either impossible or unfeasible.
3. To enable the student performance level to be commensurate with his/her goals and potential.
4. To give technical assistance to the colleges and universities so that they can develop their own programs or improve existing services for their disabled students.
5. To foster service programs in all colleges and universities in the area.

Mid-point evaluation of the Project has revealed that its programs have been effective in meeting these stated objectives for both the institutions and their disabled students.

During the second year of the Project, a Distinguished Lecturer Series was planned to integrate these objectives into a single meaningful activity which would dramatically present to students and their institutions a glimpse of what could be achieved. The speakers were selected from the fields of civil rights, education, employment, social service, recreation and leisure not primarily because they were disabled persons, but because they were authorities in their respective fields. Each one represents a dynamic challenge to the sterotypes commonly projected by those not familiar with disabled persons. And each is a monument to the strength of the drive of that particular power of the human spirit which transcends obstacles of whatever kind and achieves despite the odds, whether they be individual and natural or societal and imposed. They are persons of talent, of expertise, and of credibility who have successfully resolved the challenge of their disability and now serve as role models to disabled persons everywhere and especially to those enrolled in colleges and universities. They serve too as viable examples to college administrators and faculty of what disabled college

students are capable of becoming. Most important of all, they have a message for all citizens. They are saying loud and clear that discrimination against the disabled and their exclusion from many vital areas of society is a loss to our land.

The campaign to provide disabled persons with equal opportunities for personal and professional growth and development calls for action on several fronts: transportation into the worlds of work, of leisure, and of culture must be facilitated; programs of higher education must be made accessible; structural changes such as the removal of architectural barriers must be undertaken. Finally, efforts to educate the public must be increased. By daring to face this challenge, the American people will stand to gain new resources and will, at the same time, destroy the last vestiges of discrimination and affirm their new faith in the disabled person's contribution to society in our time.

Part One

Social Aspects

Judith Heumann is Senior Deputy Director of the Center for Independent Living in Berkeley, California and vice-president of the American Coalition of Citizens with Disabilities.

Handicap and Disability

Judith Heumann

Center for Independent Living
Berkeley, California

I would like to tell you a little bit about myself. I had polio when I was a year and half, so I identify myself as being a disabled individual. By that I mean I have no rememberance of being a nondisabled person and have no identity as such. I think that growing up as a disabled individual has been significant in shaping the political beliefs that I have today. But whether you grew up as a disabled person or became disabled later on, the basic discriminatory practices that exist against disabled individuals are ones with which we are all familiar.

I went through a growing-up process similar to that of many of you who have grown up disabled: I had home instruction for four years—because I was considered a fire hazard by my local school. I then attended segregated classes in a public school in Brooklyn, where some very interesting things went on. It seemed to me as I was going through those classes (especially as I became older and was able to look back on what had happened while I was in school) that the school system did not recognize the possibility that a disabled person could become an integrated part of the community as a whole, and this, by being provided with basic skills and educational opportunities.

The schooling I received between the fourth and eighth grades was, to put it politely, rather lacking. But some very interesting things happended then. I was in classes made up entirely of disabled children. I would identify many of them as having been inappropriately placed in those classes. Consequently, they were not receiving an appropriate education. But some of the peer support that developed was very beneficial. As disabled individuals we had an opportunity, even at that young age, to talk about the experiences we were going through and the problems we were encountering—not really knowing what to do about them, but at least having a place where we could begin to verbalize the things that were going on within ourselves.

One of the interesting things that I recall was the "class" structure we had unconsciously established within the special education class. In the class were persons with polio, with muscular dystrophy, with cerebral palsy, with spina bifida. The nondisabled students from up-

stairs would come down as monitors. If they had been good, they could come down and help us take our coats off and clean the erasers and the chalkboards. That was part of the big "integration" that was going on at that time. And once a week, on Friday, we went to assembly. We would be pushed there in our wheelchairs by the nondisabled kids or, as we referred to them, "the kids upstairs." I remember being very conscious of body image and of my being, on a certain level, less severely disabled than some of the others, such as those with speech problems or those who had difficulty controlling the movement of their arms and legs. On a certain level, I appeared "more normal" than some of the other people in my class, and this was a way for me to feel better about myself. It was a way for me to make a better impression on the kids upstairs.

As is often the case, there were no other disabled children living on my block. We disabled students were bused to school; and after school we went home to our separate communities. I did not have an electric wheelchair at that time (most of us did not), so I was dependent on others to take me where I was going, because I did not have (and still do not have) enough strengh in my arms to push my chair really well. I remember being pushed to the stores and on a certain level thinking, "If I'm not with other disabled people nobody's going to know that I'm disabled." Obviously the reason I felt like that was because of the real stigma that is and was attached to being disabled. I do not think this is uncommon; probably many of you in the audience went through the same kinds of experiences. When someone whom I did not know would come up to me and ask, "What's the matter with you?" or "Are you sick?" or something of the sort, I used to get very upset; sometimes I would want to cry, other times I would want to crawl under the ground. This was because of my basic inability to accept myself as a positive human being and as a powerful person. If I could have felt at that time that I was an attractive person, I would not have been bothered by somebody coming up and saying something like that to me; I would have taken it as a nice gesture. But because I looked at myself as someone who was not equal, someone who was not valuable, anyone coming up to me and asking, "What's the matter with you? Are you sick?" was seen as making a personal attack, and it was very difficult for me to deal with that.

When I went to high school I was again bused, so most of the people going to that school did not live in my neighborhood. What that meant was a continuing social deprivation. Again there was a special class, but because I was on an academic track, I was integrated for all my classes after the first year. Even in the first year two of my classes were integrated.

My parents tried to integrate me as much as possible; I was in Brownies and I went to religious school, so I want out and was with nondisabled kids a lot after school. And I had many friends on the block. But in school, in a more organized kind of structure, I was

terrified. I was afraid of the nondisabled students, and not having an electric wheelchair, I was very dependent on other people. I felt very self-conscious about pushing my chair because I could not push it very well. When I was trying to hold books I was very clumsy; and if something fell I would have to ask somebody to pick it up. There was this continuing negative bombardment of my self-image.

In high school I registered in a Spanish class. Spanish seemed to me to be a logical choice: I could not speak Spanish; many people in New York City spoke Spanish, and I felt it would be nice for me to learn to speak the language. But when I got into the class, there were no other disabled people there, none. I was in a panic, because it meant that I had to get to that class by myself and I had to get to my next class by myself. I needed somebody to push me, and because none of my friends from the special class were in that class, I had to ask somebody that I did not know. To stop somebody in the hall and say, "Hey could you give me a push?" was really difficult for me. If they said no, I was devastated. Well, two of my friends in the special class were taking French, so I switched from Spanish to French because I could not deal with going into a class where I did not know anybody else who was disabled. So I never took Spanish. I went through high school taking French, and I took French when I was in college; but I do not speak it very well—actually I do not speak it at all. I do not know if I would have been more successful in learning to speak Spanish, but I think I might have been, because there were people in New York who spoke Spanish. You do not find—at least not where I lived—a lot of people on the street that you can converse with in French.

I think that whole issue—the terror of being in a class with people that I did not know and of not being in control of myself and not feeling good about myself—had a very significant influence on what I was going to do as I grew up. I never dated anybody in high school. And there was always a kind of contradiction, because in special classes I was outgoing and unafraid of anybody in the class; I am a pretty outgoing person, a pretty verbal person. But in my other classes, academics was one thing, but the socializing was always a big problem.

I remember when I was graduating from high school I was supposed to get some award, and when I got to the auditorium (I went to Sheepshead Bay, but the graduation was in Brooklyn College) there were steps onto the stage, and the principal did not want me on the stage because I was in a wheelchair—that was obviously what it was. I had these very mixed feelings: part of me wanted to fight about what was going on, but part of me did not. I was very embarrassed. I was going to have to confront this issue of my not being allowed on stage because I was in a wheelchair. The plan was that they would go to the front of the stage and dip down and hand me the award in the audience, and I knew I did not want that. That was more humilitating than having to fight to get on stage. What I wanted was to go home. That was all I wanted. When I get very, very angry I sometimes have

difficulty channeling may anger, finding ways to express it, so I start to cry. That in and of itself is interesting, because I think disabled individuals have esentially been stripped of the right to be powerful people. We have been taught that we have to accept whatever little is given to us; that we should not rock the boat, because if we rock the boat too much we are going to lose even the little bit that has been given to us.

I think many of us still basically believe that. If we did not, I do not think we would be in the position we are in today. I firmly believe that we are still an extremely oppressed group of people. I *did* get on that stage; my parents were there, and they, I am sure, were as nervous and as embarrassed as I was. It was horrible. I got on the stage; but I will never forget that incident as long as I live, and I will never forget that principal.

When I was in high school I used to go to summer camp, as I am sure many of you did. In camp, socializing was the same as it was in special classes—it was fine. Everybody was together; you did not have to tell anybody about your disability, and people did not stare at you. You had your own little community that you lived in. I dated all the time when I was in camp. Then I would come back to the city, and although I always had a lot of friends, I never dated. A friend of mine who was a year or two older than I was said to me, "Listen, you know, the men in college are more mature; when you go to college they're not going to be looking at your disability, they're going to be looking at you as a person; don't worry about it." Some of you know Neil Jacobson from Hofstra. Neil tells the same story—about how he went to college expecting it to be a different world, expecting that when you graduated from high school and went to college, everybody became mature; disability became a secondary issue, and you were regarded as a person. Well, it was *not true.* It was far from the truth. There I was in college with all of these mature men and women. They may have been mature, but I soon found out that they knew nothing about disability.

Basically, as people get older, they become more afraid of disability. Children are very open and very inquisitive, and I think that is good. Now that I look back on it, I think it is unfortunate that I used get so upset when other children came up to me and asked what was the matter with me. I tell young people this because I feel we need to demystify what we are. We are all individual people; we have a disability and I think that adds to our character, positively. I think we need to overcome the fears of adults, and that is best done through children.

A couple of times when I lived in the dormitory I had people knocking on my door on a Friday or Saturday night and asking me if I knew anybody who needed a date. Well, *I* did not have a date; but there was never any recognition on their part that they could ask me, that *I* might need a date; that *I* might want to go out. And I never said to them, "Well, I'm not doing anything." I would always refer

them to Jane or whoever I knew did not have a date—because I did not respect myself enough and because I was terrified of what in the world would happen if I went downstairs and met a nondisabled man. He would be shocked when he met me. It would be the biggest catastrophe for that individual and the biggest catastrophe for me. So I would sit in my room and bemoan the fact that I did not have a date. But there again were the same basic questions: Why was I not asked? Why did I not speak up? Why did I refer them to somebody else? I could have said, "Look, if you don't want to ask me out, knock on somebody else's door, they'll tell you somebody who doesn't have a date."

Another interesting thing in college was being in a sorority. That was difficult for me—not because of the sorority. I decided that I needed to be part of a sorority because it was a way for me to get involved with people on campus, and if I did not get into a group I was going to wind up being more isolated. I had met a woman at camp the summer before I went to college who was in a sorority, and there was a chapter of that sorority on my campus; she was going to write a letter of support for me. That was already a great help; I was not going to have to go in and be totally on my own. Going through rushing was insane. I felt like an invisible person who was terribly visible. And I had this wheelchair that was too visible. I wanted to shrivel up because I knew I needed to be there, needed to become more socialized, but it was a terrifying thing for me to go through. Let me explain, for anyone who has not been in a sorority or a fraternity, that you go through an initiation period where you have to come to a table for a couple of hours each day and be available to do various things for people. But one thing that supposedly always went on in sororities and fraternities was that people did a lot of dating; you would set your sister up for a date with a brother.

I was very active, and I got more and more political. I got involved in community activities and was elected to student government and worked in the president's office. So of course I began to run into the dilemma of sterotypes. As a woman I was not supposed to be doing those things, and certainly as a disabled individual I was not supposed to be active and aggressive.

When I was a junior in college, I decided that I wanted to be a teacher. I knew that at the time there were no disabled people in the city of New York who were teachers, that is, who had become teachers when they were disabled. So, as a junior in college, I called up the ACLU and said, "I'm in a wheelchair, and I'm going to be majoring in education and I think I'm going to be discriminated against when I go after a teaching job. Will you be my attorneys?" The person I spoke to said, "Wait until you graduate and see if you have any problems." So I did. I went through school—Long Island University in Brooklyn. At that time there were not enough teachers in New York, so they did not require you to do student teaching. And I had to take only twelve

credits. I was a speech major with a minor in education. I was doing my speech field work in clinics; I did some work in the city.

I graduated, then took my teacher certification exam. I took the written exam at Brooklyn Technical High School, which is an inaccessible school; I had to be carried up the steps to take this exam. Then I took my oral exam somewhere else. Then I took my medical exam down at the Board of Education.

The doctor who examined me was the most incredible doctor I have ever met in my life. She was flabbergasted when I came in in a wheelchair. (I found out later that a friend of mine had also had this doctor for the medical exam. My friend had come in wearing a Bermuda shorts suit, and the doctor was flabbergasted over her coming in wearing a Bermuda shorts suit. So you can imagine how flabbergasted she was when I came in a wheelchair.) She said, "You know, no one's ever come in for a teaching license in a wheelchair before." And I said, "I know that."

Nevertheless, she was the one I had to deal with. She asked me about my medical history; and then she found out—that I had a spinal fusion, that I wore braces and used crutches (my nickname was Turtle because I was not very independent on my crutches and braces, to put it politely). She told me that I had to come for another medical exam, and that I *had* to bring my crutches and braces. Even if I only walked a couple of steps, she wanted to see me walking. This woman was a voyeur if ever there was one. I went for the second exam. Perhaps some of you know Ted Childs; he used to be at Long Island University in Brooklyn. He is black, and he had been very active in black political activities. I would consider him, in a certain respect, to be my mentor, because he really put me in touch with a lot of discrimination issues—the problems of the minority group he was a part of, the problems he had encountered and the political activities with which he had been involved. He was an inspiration to me. Ted Childs accompanied me for my second medical exam; but of course he was not allowed in the room with me. This woman and two other doctors (men) were in the room to examine me, so it was three to one. They asked me the most bizarre questions. Then I told them I had not brought my crutches and braces, so they marked me down as being insubordinate. Then, out of the clear blue sky the woman said to the other doctors, "She wets her pants." That was such an insulting remark I could not even react to it. I started to cry; again, I was so angry I did not know what else to do. Anyway, I failed the medical part of the exam, needless to say. I wrote to ask the reason, and I got the reason—one sentence: "Paralysis of both lower extremities; sequelae of poliomyelitis."

I called the ACLU again. But the ACLU said there was no reason for me to come down for an interview, because it was not a case of discrimination that they felt they could win in court. It was purely a medical decision, and no judge was going to rule in my favor on an issue like that. I remember those scenes so vividly; I remember trying to talk

to this person on the phone in between crying. It was like saying, "You've got to let me into your office, at least let me talk to you; how can you tell me that I am such an invalid person that you're not even going to let me sit down and talk to you." But at any rate, they did not let me sit down and talk to them, and I dropped them. The upshot of the whole thing was that I did get some lawyers, and we did sue the school system, and that was one of the issues around which Disabled In Action in New York was formed. There were a lot of us who were being discriminated against; together we were beginning to feel power as a group, and we decided it was important for us to form a political organization that would be able to begin to address the issues of discrimination against disabled people—not just in the area of employment, but as a systemic problem.

I have gone on to do a lot of other things since then, but I think DIA was a really great experience for me, because it was and continues to be an organization of people who are very concerned about making political changes—not always knowing how to do it and continually being confronted with such questions as, "How do we feel about ourselves?" and "How much are we going to push on issues?" and "How are we going to be viewed by the nondisabled community and by the disabled community if we push too hard on certain things?" I think we began at that time to say that discriminatory practices against disabled individuals have got to end, and that one of the ways that it was going to occur—the only way in my opinion—was by disabled individuals assuming power. I think one of the ways that disabled individuals begin to assume power is by respecting themselves as powerful individuals; there is nobody, whether disabled or nondisabled, who does not have some kind of contribution to make to society. Until we, as a class of people, begin to recognize the strength that we hold within ourselves—as individuals and as a group of people—we will continue to allow discrimination to occur against us. I think that is the crux of the matter. We have got to say "No, no, no" a lot more frequently, and "Yes, yes, yes" about what we believe, and not accept what we do not believe to be ethically or morally right.

In 1973 I moved from New York to Berkeley, California. That, in and of itself, was probably one of the most important things that I have done in my life. The important thing about it was the fact that I left the place where I had grown up and moved to a community where I knew no one. So, again, there was the whole issue of socialization, but also the other issue of services. There never had been any services in New York for me, but I had been able to create a community around myself, in which I was able to survive; I was able to get up out of bed in the morning and function very much as I wanted to—not always feeling good about the number of people I had to ask for all the things that I needed, but nonetheless able to make it through the day.

I had acquired an electric wheelchair when I was twenty-one years old, which was probably also one of the more liberating experiences of

my life. Suddenly, (those of you who did not use electric wheelchairs and now use them will know exactly what I am talking about) I was much more of a person; I could decide when I was going out of my house and decide where I was going–as long as it was somewhere within chair-driving distance. I was becoming more of a "mensch."

I went out to Berkeley absolutely terrified. I had not lived at home since I was eighteen, but my parents would come to my apartment; they would help me with my shopping, they would help me take a shower, they would help with my laundry–all the things I could not do by myself and had no attendant to do for me. I went to Berkeley, to this community where people had told me, "Oh, everything will be great; you can come to Berkeley and you will be able to survive." I had not fully believed a lot of it, but for some strange reason I decided to go out there for a couple of days and see if I liked it; if I did not like it I could always come back home to New York.

I was met by two guys, both of whom were disabled, driving a van with a hydraulic lift on it, which was something practically unheard of in New York at that time. They picked me up and we went to Berkeley, and there was somebody there to do attendant work for me. I had lived in New York all those years and never had anybody there to work for me. Now I found myself deciding, even for the week that I was there, when I was going to get up in the morning and when I was going to go to bed at night. All of these great things were beginning to happen. So I decided that I would go to school there, at Berkeley. I got involved in an organization called the Center for Independent Living, which I am now working for, and began to recognize some very interesting things that were going on in that community. Berkeley is a very political community for nondisabled individuals. Some disabled people were active in the free speech movement and in the antiwar movement. But for disabled individuals in the 1960s, the community itself was still essentially inaccessible. During the late 1960s, a small group of disabled people began to organize on the campus, setting up a program called the Disabled Students Program. Then in 1972 they set up the Center for Independent Living (CIL) which is not part of the university.

Here was a group of very severely disabled individuals who were also very mobile and becoming very political. Both CIL and the Disabled Students Program were programs controlled by disabled individuals. This was, and still is to me now, a very fundamental issue and one that we need to be addressing. In these organizations, staffing is largely by disabled individuals; policy is dictated by disabled individuals; services are provided by disabled individuals. Therefore disabled individuals also decide the services that are going to be provided. Most of the people on the staff who are disabled–we have about a 50-50 mix; 50% disabled, 50% nondisabled–are also recipients of services from the organization, so we have a vested interest in its survival; without it our services disappear. There are now nineteen other programs in California

similar to the CIL program. Although those programs are two to three years younger than CIL, already the beginnings of very heavy-duty political action taking place in California can be seen. What it amounts to is that disabled people are getting services, feeling secure about the fact that services are not going to be taken away, feeling free to speak out on issues, but then also being *able* to get into other issues apart from those dealing with sheer personal day-to-day survival. Because a lot of our survival needs are being taken care of, we can get involved in issues of curbcuts, integrated housing, SSI, accessible transportation, education, jobs. All of the things that are so important to us but that we do not have the time to deal with effectively because we are just trying to survive on a day-to-day basis—these are now a reality of our lives. We are exceptionally political. We are not as political as I would like us to be, but when I look at disabled communities in other parts of the country, California's disabled population is exceptionally political. In my view there are two reasons for this. One is that California has a program called In-Home Supportive Services, a program that provides attendant care money for disabled individuals who are below a certain economic level—a level that most of us have no difficulty falling below. So there are about 70,000 to 80,000 people in California who are receiving attendant care funding. The maximum you can get for attendant care is about $542 a month, and our SSI benefits are $292 a month; so we have a pretty substantial economic base from which to hire attendant care services. We can get the attendants through the centers, and in Berkeley we can get our wheelchairs repaired on a day-to-day basis. There is some transportation. Berkeley is almost entirely curbcut, and in the Bay Area, we have an accessible transit system—not the buses yet, but the subway system (or the trains, as they call it there).

The next area I would like to talk about is what I view as the emerging independent living movement in the United States. I view that as a movement of disabled individuals establishing programs that will meet the needs of disabled individuals and allow us to live in the community in an integrated fashion. CIL is a nonresidential program, and that is critical to the organization as far as I am concerned. Our philosophy is that disabled individuals need to become integrated into the community and to be able to identify any and all of the services they need to ensure that they will remain integrated in the community. (At present we do not provide all the services we would like to be providing, but this is a goal.) I do not believe in transitional living programs; I think they are a farce. I feel that a disabled individual should be able to move into a place in the community. Independence does not mean living by yourself, and it does not mean doing things totally by yourself. Independence to me means knowing what it is you need in order to be able to do what you want, and having access to what you need in order to be able to do what you want. It does not mean spending two hours in the morning just so that you can say after those two hours that you have got yourself out of bed if somebody

else can get you out of bed in ten minutes. I see absolutely no reason to prove myself as a supercripple by wasting energy, and then not having enough energy to deal with political matters. That is where I feel my energy needs to be invested. That is where I feel the energy of all disabled people needs to be invested.

This is not to say that I feel that disabled individuals should not do for themselves; but it is for us to analyze carefully what it is we can do by ourselves and what it is we need to do with somebody else. Working in attendant referral at the center, I find that people who come in for services sometimes do not know how to make the most basic decisions. Attendant referral at CIL goes like this: you come in or you call in and you say, "I want an attendant at X hour in the morning and X our at night for X number of days a week, and this is what I want him or her to do." We give you the names of people we have interviewed, and you are supposed to call them and interview them. You hire the attendant yourself, you pay the attendant yourself, and you fire the attendant yourself if that person is not doing what you want done for you.

All this means is that you have to know a lot about yourself; you have to know what time you want to get up in the morning—as opposed to having someone tell you what time you are going to get up in the morning; you have to know how you want to get out of bed; how you want to go to the bathroom; how you want to get dressed; what you want to wear; whether you want to eat breakfast; what you want to eat; where the food is; how you are buying it; with what money you are buying it; whether you want your house cleaned; how you want your house cleaned; how many times a week you want your house cleaned, and on and on and on. We have been so oppressed—many disabled people, as you all know have never had the opportunity to makes these decisions for themselves. In establishing for themselves what they are going to be doing they are getting that part of their lives together. Nondisabled people by and large take this absolutely for granted; they do not even think about it. They set their alarm clocks and get up pretty much when they want to get up or have to get up because they are going to work or whatever. But many of us have never been able to to that, and learning how to do that right (and by "right" I mean what is right for you as an individual) is the beginning of becoming independent.

What is going on right now in the independent living movement in California and in other parts of the country is that there are more and more disabled individuals saying, "We have got to set up these programs." In the beginning, when CIL was set up, it was viewed as anti-establishment. And it is still viewed that way in many quarters, as are the other independent living programs. We have brought in people, and our concern is not necessarily whether or not they have a degree; our concern is whether or not they as disabled people can relate to other disabled individuals and assist them in getting their lives together, help

them to become independent, powerful, political persons. And we have been meeting with incredible success. We are getting money, though not as much as we need. Our record keeping is not quite the way people would like it to be, and we have had to learn how to become more establishment-oriented. I think that is necessary so that people will know where the money is going. But nonetheless, many people are moving to California and are becoming more productive, and the system is looking at the programs and saying, "There's something there that's going right. They're producing more 'rehabs' than rehab, and why is that happening?" We are saying it is very simple: Disabled people know what disabled people need and want. (That is not true for all of us, but it is for many.) As a result of that we are able to help people move on. We are peers. We are role models. That is critical. When we go into most establishment organizations, we hardly meet any disabled individuals; there are no peers that we can look up to. I never met a disabled professional until I was in my twenties; I had only nondisabled role models—who were not role models to me because I am not nondisabled. That oppression, which goes on on a day-to-day basis, is something that we in the independent living programs have been able to begin to change.

Now the government is becoming very interested in independent living programs, as are many organizations, such as Goodwill, Easter Seal, and so on. Those of us who are running what we consider to be independent living programs regard ourselves as an elite group, because we know that our philosophy is right and their philosophy is wrong. We have no time to discuss whether we should change what we are doing, because we believe that what we are doing is right; that is, that we are community-based service centers, self-help organizations that are nonresidential.

Legislation is being introduced to provide funding for the independing living programs—funding that we have been begging for. It is a stark reality that our programs are running on a shoestring, that we are concerned on a day-to-day basis about programs running out of funding; because the money comes in for one, two, maybe three years, and we have twelve or thirteen programs at CIL, and the other independent living centers each have numbers of programs. As our money runs out and it becomes more difficult to renew the funds, we are asking the government to provide support money. But now we find that the government is not insisting on the criterion of disabled control. We say that you cannot have an independent living program unless it is controlled by disabled individuals. You can call it an independent living program, but we will not call it an independent living program. What we as disabled individuals have begun to create is going to die on the vine unless it is done properly. So one message I have for all of you is that, as a very short-term strategy, you should contact Senator Javits on Monday or Tuesday with a simple phone call to his New York office. There is a piece of legislation in the Senate now,

and all you need do is say that you are from New York, that you know there is rehabilitation legislation before the Human Resources Committee, and that you want that legislation to say that the independent living programs must be controlled by disabled individuals. This means that the programs' boards of directors must be disabled-controlled. The programs must be nonprofit community organizations, and the staff must be made up primarily of disabled individuals. I think this is very critical.

If this money goes out the wrong way, there is a real possibility of bringing to a halt something that has been growing rapidly. No, I should not say that. But I do think it would mean disabled individuals having to continue to struggle on issues that I wish we no longer had to struggle on. I think it is ironic that nondisabled individuals should be telling us that there are various ways in which services can be provided to disabled people, and that the issue of disabled control is something they want to experiment with. In this day and age, it could no longer happen that legislation for women would be passed that said, "We would like to experiment with whether or not a women's organization should be controlled by men." It just could not happen. And this is analogous. There should be no discussion about whether or not disabled people should control programs that provide services to disabled people. The very fact that those discussions are going on shows that we are not respected, not thought of as being capable people who in fact can determine policy and operate programs. I am not saying that we are not going to need help in learning how to do things better. I am not saying that I do not need to learn things on a day-to-day basis; everybody does, whether disabled or not disabled, but control is a critical issue.

There are two other issues that I want to identify quickly. One is the issue of who makes up the disabled movement. The other is the issue of nondisabled individuals in disabled organizations.

I think the disabled movement to this point has pretty much been represented by white disabled individuals. On a certain level I can understand why this has happened. Many of us who are white did in fact come from middle-class families; compared to the families of persons who were poorer, our families were able to provide us with greater opportunities. (It seems rather ludicrous to call what we had "opportunities," but nevertheless we will have to define it as that.) But we have a movement here that as far as I am concerned is unlike any other movement. Disability cuts across race, it cuts across sex, it cuts across economic background; we therefore have the chance to begin to do what many of us have wanted to do—that is, to turn American society around to become one that is responsive to the needs of all people. I think quite frankly that most of us recognize that the plight of poor people in this country, irrespective of why they are poor, is due to significant discrimination that affects all of us. In order for us to be able to create a truly viable movement, it is incumbent upon us to make sure that our organizational structure is changed, from the

leadership level down to the membership, and that we begin to represent a greater cross-section of the people who make up the disabled community. If we do not do that, I am afraid that the disabled movement will continue to splinter. The disabled movement is now becoming a movement because we as disabled people are saying it is not relevant whether or not I have polio, whether or not I have cerebral palsy, whether I am mentally retarded or mentally ill or a substance abuser; what is relevant is that I am a disabled person. We disabled people must unite as a class; we must stop fighting amongst ourselves about which disability should be getting more and which disability should not be included. All of that is so irrelevant that we play right into the hands of the system. As far as I am concerned, the more people we can get into the movement who call themselves disabled, the more powerful we are; if we fight about who does not belong, we are fighting to diminish our numbers. We do not want our numbers diminished, we want people to know that there are at least 47 million disabled individuals in the United States. Those are government statistics, and I believe they are an underestimate, because the government has never done an accurate census of disabled individuals. But, if in fact we had 47 million disabled people who were identifying themselves as disabled people, we would be in a pretty strong position. We would be able to control a significant amount of what is going on.

I am a disabled person and I am a woman. I believe, however, that discrimination against me stems from my disability, not from my sex. If I were a non-white woman and disabled, I believe that the primary reason for discrimination against me would still be my disability. I feel it is very important for us to begin to recognize this: Disability is the primary problem in our lives. Once we can identify ourselves as powerful disabled individuals, we can then go back into our secondary communities, whether it be the black community, the Chicano community, the women's community, or some combination of these. We can then go back into our communities and start making them deal with us the way they should be dealing with us. When we look at the minority groups, we find that they too have discriminated against us as disabled individuals; there is no group you can identify to me that has accepted us as equal individuals. It is therefore incumbent upon us to identify our primary group as the disabled. When we have identified our primary group as the disabled and have been able to become strong, we can then go back into the various communities in which we belong and bring them around to accepting us as part of the community. That is the way to begin to change systematically the problems that exist within the society as a whole.

The other thing that cannot be overemphasized is the need for disabled individuals to be the primary personnel in disabled organizations. There should be no discussion about that. This does not mean that there is no role for nondisabled individuals. I feel, however, that nondisabled individuals who believe that our movement is a good

movement and that our cause is a good cause do not want to hold primary roles within our organizations. They want to be there to be supportive, they want to be there to talk with us, they want to be there to help us move about and do the things we have to do. But they know that we must be the spokespersons for our organizations. That does not mean that we should not go out and unite with other organizations. The 504 demonstrations last year in California were successful for a number of reasons: because the disabled community was united; because the disabled community absolutely unequivocally believed that 504 was our civil rights provision; because we knew that if we did not fight for this civil rights provision we were in fact going to slide backward instead of making further progress.

But the other factor was that because of the programs evolving in the Bay Area that were controlled by disabled individuals, and because changes were being made (curbcuts, electric wheelchairs, Bay Area Rapid Transit being accessible, etc.), we were more visible in our communities. So we went out into other organizations, we approached, surprisingly, such groups as United Cerebral Palsy and Easter Seal and those kinds of organizations, and they came in and worked with us. We received support from the churches and synagogues and from the labor unions. We had support from all over the place. The Black Panthers fed us for four weeks during the sit-in. And we were supplied with food from Safeway stores; it was a totally bizarre event, it really was. People that I could not conceive of being together were living in a building on one floor for four weeks.

I was recently at a meeting of a particular organization of disabled people, and there was a debate concerning voting rights within that organization. I am violently opposed to what occurred there. I believe there is something radically wrong when nondisabled individuals from nondisabled organizations believe they are entitled to vote in our organizations. And there is something even more wrong when disabled individuals sanction that opinion. At the meeting where this occurred, nondisabled individuals were allowed to vote on whether or not they should have a vote within that particular organization. I think this is a major problem. I think it is difficult, very difficult, to say to someone whom you like and respect, "I don't want you to have a vote in my organization." It takes a lot of guts to say, "I feel that if you really respect me and if you really understand the political evolution of what's going on right now, you will see that our people must have control." Any attempt to take that control away is negative to us. And I think the fact that we allowed it to happen in California, in the Bay Area, which I consider to be the strongest political unit in the country for disabled individuals, is indicative of a drastic need for change in policy. I am urging you to make sure that it does not happen in New York. Nondisabled persons are more than welcome as associate members, or to serve on committees. But they should not be allowed to vote when you are voting on such matters as your board of

directors, because your board of directors establishes the policy of your organization.

PANEL DISCUSSION

Panelists: Ed Lewinson, Seton Hall University
Bill Mennella, New York University School of Social Work
Gerard Nuzzi, Equitable Life Insurance
Phyllis Rubenfeld, Hunter College
Ena Sanchez, LaGuardia Community College

Moderator: Harold Wilke, Healing Community

MR. LEWINSON: I am very glad to be here. It is hard, very hard to lead off, because the things that Judy Heumann has said are things with which people with any kind of disability—or for that matter members of any minority group—can identify, without question.

I would like to make just two comments—not in disagreement but in amplification. One of the things that is common to all kinds of disability, but a concept that people do not consciously accept, is that the point is to function, to make the maximum contribution that one can, rather than to try to overcome the handicap as much as one can. All of us have to establish priorities. We have to do this in all aspects of our lives. Part of being an independent person is being able to decide the areas in which we function best when we are independent and the areas in which we function best when we let someone else help. That way we can function at our best when we are being independent, is I think, an important concept.

Another thing that I am sure everybody recognizes (but it is important to emphasize it once in a while) is that the problems and needs of people with various disabilities are in many ways similar but in many ways different. Part of having a coalition and being able to unite and work for the needs we have in common is to recognize the different needs of different disabilities; a blind person is not necessarily in a wheelchair, and a person in a wheelchair who has 20/20 vision does not need to use braille, and neither blind people nor people in wheelchairs are necessarily hard of hearing. I think that this point is worth making because it is another area in which the public sometimes gets confused. People tend to think that if you have one handicap, you have them all. Part of the educational process is learning to recognize the particular needs of each particular disability.

MR. MENNELLA: I do not know where to begin. Judy Heumann has said just about everything that needs to be said. I can only urge people to consider the word "oppression." I think that is the word and the concept that came through time and again in what Judy had to say.

I work at the Institute for Rehabilitation Medicine here in New York, and I deal constantly with people who have recently become

disabled. One of the first major impressions that struck me was that able-bodied people do not realize the nature and extent of the oppression that disabled people experience. I am not going to bore you with my own personal history, but I want you to know that this is definitely the case. As an oppressed class of people, I think it is incumbent upon us to take upon our own shoulders the responsibility for unburdening ourselves of this oppression. People who are disabled are handicapped only by societal values that they allow to be inflicted upon them. As long as we continue to allow this, we have a very poor argument against it. If we take the initiative and we sustain the struggle as a united front, then I think we will have a much better chance of lifting this oppression.

MR. NUZZI: All I can add to what has already been said is that disabled people have to start living a positive existence. We cannot just let our parents and everybody around us get us down. The only reason that I am working for Equitable right now, in a fairly good position, is because I fought people all the way up to the president of the Brooklyn Chamber of Commerce, right on up to the president of Equitable to get my position. I did it because I had an MBA from Long Island University and I knew that I was worth something more than just my physical limitation, which is cerebral palsy. Harold Yuker has said in his studies that what determines the way people interpret us as the disabled is largely the way we interpret our own disabilities. So if we think positively about what we are and we do positive things all the way through our lives, I think we will still encounter a lot of difficulties, but maybe we will enjoy our lives a little more.

MS. SANCHEZ: I am a member of the National Paraplegic Foundation and it disturbs me that my organization is not well represented at this meeting.

You talk about people, disabled people, not banding together, and I hear these exhortations, "Band together! Organize!" I get really upset about it because if there is anything we disabled people can do it is talk a lot. I talk a lot, but I also would like to *do* a lot.

I find, myself, that whenever I go ahead and do something I look behind me all the time and there is no one there—so what do I do? I go ahead and do what is good for Ena, which is bad in a way. When I speak of my people, I mean disabled people. I am a disabled woman, I am black, I am a Jamaican, I am a West Indian. I fall into all these categories but the two I usually want to pick out and deal with are that I am black and disabled. I do not even want to add that we have got to stick together and fight. I would like to see something come of it, to do something; not just to sit back and talk a lot, but to do something.

MS. RUBENFELD: The theme of my talk is based on part of an editorial that appeared in *Freedom's Journal* on March 16, 1827;

it reads, "We wish to plead our own cause. Too long have others spoken for us." In order to understand why we, people with disabilities, are received with mixed emotions or blatant prejudice or both, it is necessary that we be aware of our roots. Historically, disabled people have been viewed by society at large in a variety of ways. For example, people saw us as persons possessed by evil spirits and therefore as objects to be ostracized, feared, devalued, or at best, ignored. Conversely, we were seen as religious objects of suffering, chosen because of our inherent goodness to take upon ourselves the suffering of the world. In time these early beliefs were deliberately institutionalized into the current repressive system. How did this come about?

First, society translated the "evil spirits" attitude into the reality of isolation by sentencing disabled people to life imprisonment in institutions. Motivations were not humanistic. Neither are they today, as can be documented by numerous references in the literature to physical and mental abuse of the disabled. Similarly, the "religious" object of suffering" attitude was translated into the stereotype of the passive and saintly cripple, a concept that deprives us of our humanness. When we act in opposition to this artificially imposed role model, we are seen as hostile, maladjusted individuals with chips on our shoulders.

Both then and today these overt attitudes have camouflaged underlying economic and political reasons for our oppression. We are a potential political and economic power force in this country, capable of threatening those who have a vested interest in maintaining our position as a powerless minority. How can disabled people forced into sheltered workshops compete in the open labor market? How can disabled people, denied access to higher education, affect policymaking under the current political system? How can there be a reversal in the tide of oppression as long as we, disabled people, are prevented from realizing our potential?

As disabled people who are capable of self-determination, we must take power into our own hands. To do so requires a specific type of organization. The most advantageous structure appears to be the coalition. A coalition can be either short-term or long-term—an agreement between groups to work cooperatively and in concert toward common objectives.

Political scientists frequently stress that power to affect public policy depends on the total strength that pressure groups can bring to bear upon those having the power to make decisions at the highest levels. Perhaps the most compelling, certainly the most dramatic, contribution a coalition can make is to create an impression in the minds of legislators that a ground swell of public opinion exists on the issue in question. Public unrest on any significant issue is considered a liability by political leaders, and they therefore feel pressed to take action to stabilize the situation. It is the establishment's vulnerability to public opinion that gives organized pressure groups their political clout.

It goes without saying that the broader the constituency base of any such pressure group, the greater the potential impact of its platform. No group of people, however well meaning, can be as concerned and determined about the acquisition of equal rights for the disabled as are disabled persons themselves. Building on this belief, it is incumbent upon every one of us to make a commitment to the organizing of disabled people into coalitions. Only when we join together will we be able to determine our own life styles, run our own agencies, and work with our own people.

In order to coalesce, there are certain compromises that we, as individuals and as members of particular disability groups, must make. Usually there is an unwillingness to surrender any measure of autonomy or control, as is necessary in a coalition. Although there exist varying ideologies among disabled groups, our ultimate goals are, more often than not, in agreement. Individual organizations may have to relinquish a certain amount of power when joining a coalition. But we must never lose sight of the fact that we are in this struggle for a greater good—equal rights for all disabled people in society. The internal growth and development of the individual organizations must temporarily be a lower priority.

When contemplating legislative change, most people think in terms of the ballot box. The electoral process is, to be sure, one way of bringing about change, and if this was the chosen approach, the coalition's aim would be to vote as a block to ensure the outcome. In this case, education and the dissemination of information to disabled voters would become a high priority. It is only when politicians feel the weight of groups of people that they move in the people's direction. Only through mass organizational networks can such influence be realized.

In addition to the ballot there are other methods of bringing about change; there are protests, demonstrations, and of course, civil disobedience. The political climate and the ideologies of particular disability groups determine the most appropriate strategies for change. However, such actions cannot be engaged in unless we are an organized and cohesive body of disability groups. Coalitions also serve as reservoirs in which we can collectively pool resources, both physical and intellectual, thus avoiding duplication of effort and a needless drain on our resources and talents. It is primarily through the sustained activity of such powerful coalitions that we as disabled people will be able to bring about self-determination.

Let us look at one example of the effectiveness of coalition action. On April 5, 1977, people with disabilities, sponsored by the American Coalition of Citizens with Disabilities, mounted a nationwide demonstration to force Secretary Joseph Califano of the Department of Health, Education, and Welfare to sign into law the regulations for Section 504 of the Rehabilitation Act of 1973. This section states: "No otherwise qualified handicapped individual in the United States

shall, solely by reason of his/her handicap, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance."

The April 5 demonstration was a visible show of solidarity among people with disabilities. The demonstration stretched from New York as far west as Seattle, Washington. In this nation's capital, those of us who participated in the sit-in were denied food for two days on the orders of Secretary Califano. People were even denied medication, until riot threatened. Phone contact was also denied to us. In San Francisco an unprecedented sit-in was mounted that lasted several weeks. On April 28, 1977, Secretary Califano signed the regulations for Section 504.

To many astute political analysts the regulations appear strong; however, the test will lie in their enforcement. Following this victory we must continue to unite through coalition, which has always been a powerful political tool. We, the disabled, must put aside our personal differences and work collectively to build a powerful movement, to show to potential employers, government agencies, and the country as a whole that we are capable, energetic, and industrious individuals wanting and deserving the right to seek education and gainful employment in the competitive marketplace.

In addition to supporting enabling legislation, we must work cooperatively and in strength to destroy all forms of discrimination toward people with disabilities. This effort must also be directed toward laws that are discriminatory. For example, until 1974, the municipal code of the city of Chicago stated, "No person who is diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object or improper person to be allowed in or on the public ways or other public places in this city shall therein or thereon expose himself to public view under penalty of not less than $1 nor more than $50 for each offense." The stereotype exemplified in this code has been with us for too long. As people with disabilities we must fully believe in our self-worth and recognize that all of us have far-reaching potential.

Because of poor planning and the inadequate coordination of federal, state, and private dollars, rehabilitative and supportive services are often drained of value. These services are crucial in enabling us to contribute to society maximally. They are the backbone of our employability. This country has sufficient money, but it has seen defense spending as its first priority. The proposed federal budget for 1978 speaks for itself: $112.3 billion for defense, as opposed to $43.2 billion for health and $9.6 billion for education. We must coalesce to change this country's priorities to reflect the philosophy based on true constitutional civil rights for all its citizens. It saddens me that the President of the United States has seen fit to criticize other countries about what he considers to be their violation of basic human rights when this, in essence, is what people with disabilities suffer daily in the United

States. To make matters worse, the government offers palliative, ineffective solutions.

Some may say that the White House Conference on Handicapped Individuals was an expression of good faith by the government. Its mission was indicated as consisting of the following goals: to provide a national assessment of problems and potentials of individuals with mental or physical handicaps; to generate a national awareness of these problems and potentials; and to make recommendations to the President and to Congress that if implemented would enable individuals with handicaps to live their lives independently with dignity and with full participation in community life to the greatest degree possible. Although some of us would like to believe that the long hours spent in workshops and in state caucuses will produce effective legislation, we know that time will show that our hard and frustrating work at this conference will have brought only token changes.

We must learn that we cannot work in concert with government until the disabled are united en masse in coalition. Only then will we be able to negotiate for changes, only then will we get them. Some people may still feel that coalition is not an appropriate vehicle for solutions to their specific problems. For example, perhaps you feel that those of us with physical disabilities have needs that are too different from the needs of those of us with mental disabilities. But are they so different? We have all experienced exclusion from community services as a result of institutionalization.

Although we have our own unique needs, and they should never be denied, our goals are the same by virtue of the fact that we are all disabled. We cannot in the end be seeking different things. Until we learn that power lies within ourselves as a collective body, and not with politicians, regardless of their prominence, we will never be able to bring about meaningful change. Change will be realized when we no longer seek to shake the hand of President Carter but rather of each other.

QUESTION: I think Judy Heumann has a very important and valid point when she talks about minority identification. I know that I identify with the women's movement. I identify with various other movements; and yet I know that my primary identification is as a disabled person.

I do not know what it is like on the West Coast, but it is interesting that here in New York City what I would consider a disproportionate number of leaders in the disabled movement seem to be women. I think that is very beautiful, but I think it is also very interesting as a social commentary.

I also think it is interesting that at a meeting like this there are not more professional and preprofessional people in the rehabilitation field and in the various therapy and educational areas that relate to us as professionals. Because they need to hear us, just as we need to hear

them. At New York University, where I go to school, a conference on mainstreaming was held this week and only five people were there. Two of us were disabled and three were professionals. It is riduculous. Everyone is scared to death of mainstreaming. The whole year nobody on the whole university campus has said to me—or to any disabled person as far as I know—"What is it like to be here at NYU and be mainstreamed? They bring in speakers from outside to talk to teachers about what it is like to be mainstreamed. I think *we* can talk, both as professionals and as consumers, and not only to each other but to them.

MS. HEUMANN: There are a number of women who are activists in California, and I also feel a lot of pride in that. I feel that it is very important for disabled women to be caucusing and coalescing, and in California there is a group called the Disabled Women's Coalition. As a woman, my personal feeling about discrimination is that within the class of disabled individuals I am discriminated against as a woman by disabled men. When DIA was forming, a great number of activists within the organization were women, and on a number of occasions an incredible amount of sexism was brought to bear on us as disabled women by disabled men. I think, however, that nondisabled men do not treat us the same way as they treat nondisabled women. (Just an aside, I do not call people able-bodied. I call them nondisabled. In Michigan they call them temporarily able-bodied. But I do not feel that anyone should be called able-bodied.) Nondisabled women talk about going down the street and getting whistled at and heckled and harassed. I have talked about this with disabled women friends, and on a certain level we would like that to be occurring, because at least then we would know that we were being viewed as nondisabled women are viewed, and we could fight that. The level at which we have to fight what happens between nondisabled men and disabled women is, I think, quite different.

I have just been appointed to the National Advisory Commission on Women—that happened last Wednesday, and I was rather bowled over by it. I have accepted the position, even though they are now saying there is no money for me to go to the meetings; I fully intend to resign publicly in the event that they do not come up with some money. I am the only disabled woman who is identifying herself as a disabled woman on that commission of forty women. It appears from the list that has been read to me that I am also the only person on the commission who is a recipient of state and federal benefits. I want very much to serve on that commission because I feel it is a way to begin tying in our links with the women's movement, by forcing the women's movement to end its discrimination against us. I was at the International Women's Conference in Texas, and the number of disabled women, considering the percentage of disabled women in this country, was abominable. Almost none of us were there. That to me

was a very clear indication that the women's movement has not viewed us as a viable part of their community. I think this kind of an integration approach will assist us.

On our second comment, about the number of professionals attending this meeting, I too had been thinking about that. I think it is interesting that there do not appear to be many nondisabled persons here—and Columbia is a big university. It is very interesting that those people should have chosen not to come here tonight, and I think it is a very specific statement to the effect that they do not view us as a political group of people with which they have to contend. I think that is primarily because we have not forced them to recognize that they must make changes, that we will not continue to accept things purely on their terms.

QUESTION: Judy, I have a few questions. You mentioned crying. Is anger a sign of weakness about not being able to deal with these situations? Also, I have been to an agency we deal with. They feel we should not rock the boat. Once I went to see a counselor at UCP, who told me that I should not complain about somebody where I work. Basically, I think these agencies think we should be submissive.

MS. HEUMANN: My answer to your question, "Is anger a sign of weakness?" is no. My response would be, "Failure to be angry and to act on that anger is a sign of weakness." That anger is very productive. It is a very difficult thing for us to get back in touch with because we have been told that to be angry is to rock the boat, etc. But I think it takes very little for us to realize that unless we accept our anger, identify with our anger and turn that anger into positive action, we will continue to be an oppressed group, controlled by others.

QUESTION: I am going to answer the question about counselors attending. I have talked it up. I have tried to get them to come in. I have had a program on the disabled in one of my classes this semester. I got one person from Student Affairs; and I got the Assistant Vice-President for Academic Affairs to come with me to an evening program on the campus, that I was chairing. The counselor for the physically handicapped had something else to do that evening. It saddens me that these people who think they can counsel us are not willing to come and listen to us.

QUESTION: As Judy has said, it certainly is an idea whose time has come, that disabled people should control their own organizations. But we cannot sweep under the rug the fact that within the disabled community there are other oppressed groups who bear the double and triple burden of also being black, Latin, female, and so on. On the contrary, our sensitivity to the additional oppressions of being members of other minorities can only strengthen our own cause. We can fight racism and

sexism as well as handicapism. For example, as a disabled person—and I know many of you will have had the same experience—I am trying to hail a cab; the cab driver sees me on crutches and he takes off in the other direction. Can you imagine, if I managed to stop that cab and I was black and asked him to take me to Harlem. You know what would happen. It is not just being disabled, it is being black, it is having to ask to go to the Bronx, to go to Williamsburg. We all have certain things in common. I myself felt the sex discrimination in getting a job in a sanitation garage. There was incredible discrimination. You would not believe the things they put you through when you ask to be the only woman in a garage with 200 men.

MS. HEUMANN: Were you disabled?

QUESTION: At the time I was not disabled; I have only recently been disabled. I know that if I were to go back there as I am now, the main resentment against me would still be that I am a woman going into a man's garage. Not only that, if Alan Bakke wins his case in the Supreme Court it will not only polarize blacks and whites in this country, it will promote solidarity between ourselves and all minorities through a recognition that it is the same system that oppresses us all and that it has to be all for one and one for all.

MS. HEUMANN: I agree with you. What I was saying earlier is that I do believe that all of the other groups you mentioned have, in fact, discriminated against us as disabled individuals, whether we are disabled and women, disabled and black, disabled and Chicano. This is not to deny the fact that there is another minority attachment in addition to being disabled, but it is to say that unless we are able to feel strong about ourselves as disabled individuals we are unable to go back into that other minority group and say, "You, NAACP or CORE or whoever, you are holding your meeting in an inaccessible building and not providing interpreters for me; and you are thereby denying that I am an equal member of the group." Unless we are able to strengthen ourselves around our disability, we will be unable to integrate effectively those other aspects of ourselves.

MR. LEWINSON: I think that there is this point to be made. Each group has to be led by people who have had experience with that group. Black people have to lead the black groups, women have to lead the women's groups, deaf people have to lead the deaf groups, blind people have to lead the blind groups. For two reasons: because having members of the group lead and control the group shows the outside world that members of the group can take responsibility, whatever the group happens to be; and because having members of the group lead the group shows the minority group themselves that their people can take responsibility—it provides role models. Another thing

is that disabled people who are also members of a minority group—such as the black or Chicano or women's group—can show the nondisabled in that group that they discriminate against their own disabled in certain ways. People who are members of two or three minority groups can interact between them. Someone who is, say, disabled, Chicano, and a woman can show each group that others in the group treat her just as the majority treats the minority as a whole. This would help to educate everybody a little more.

QUESTION: I received in the mail a questionnaire from Easter Seal concerning independent living in New Jersey. Is Easter Seal sponsoring some kind of independent living program?

MS. HEUMANN: In relation to Easter Seal in New Jersey, all I can say is that the Center for Independent Living in Berkeley was contacted last year by an Easter Seal program. We gave them information on how to set up an independent living program and we have them information on CIL. But I would suggest that you look carefully at what they are intending to do—whether they are working with a disabled group and trying to help that group set up as a separate organization or whether they intend to set up a program as an integral part of their organization. Then I would look at whether or not the board of directors of that chapter of Easter Seal is controlled by disabled individuals and what their staffing patterns are. If the organization is not controlled by disabled individuals and if they cannot demonstrate that they themselves are hiring disabled individuals, I would try to get whatever independent living program they are establishing to be a separate part of the organization.

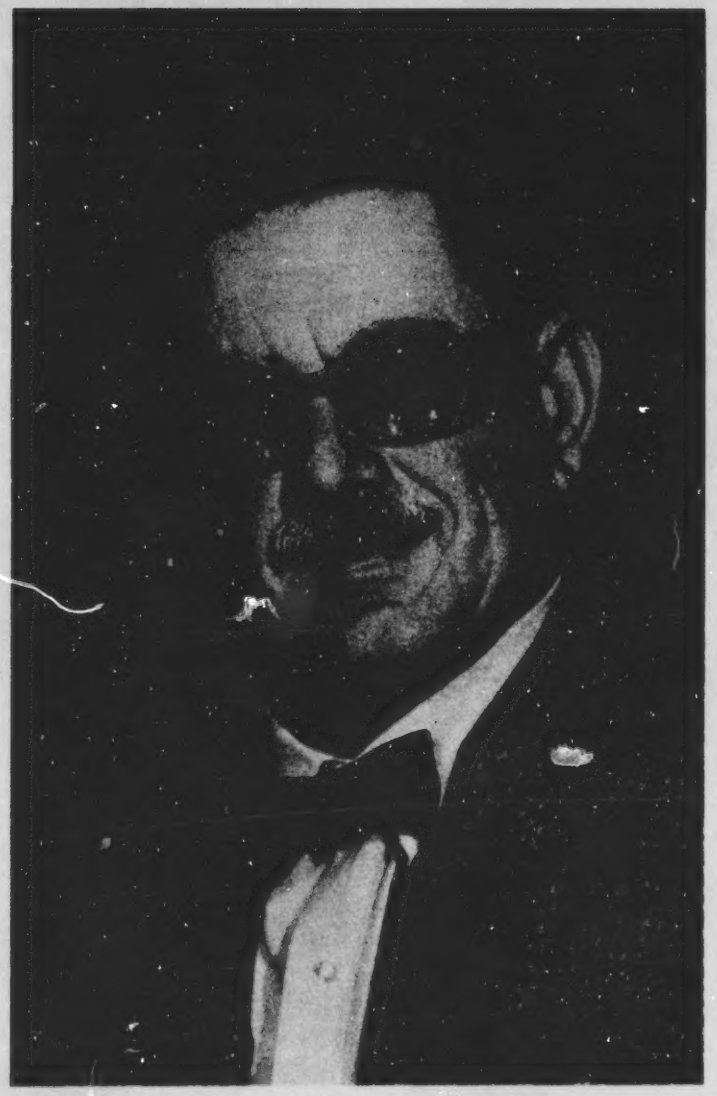
DR. WILKE: This response is of course true for every question of this kind that comes up. In every case we need to ask exactly the same kinds of questions that Judy has just raised for us.

QUESTION: I want to make reference to the fact that although we are talking about being discriminated against, we also are guilty of discriminating. Although plans are made to have our meetings in accessible buildings, which of course is necessary, we discriminate against the blind and the deaf by saying that we cannot distribute materials in braille because it takes too long and we cannot plan that far in advance, and many times an interpreter is not available and the excuse is that there are no deaf people attending. Which comes first, the chicken or the egg? If you do not have interpreters you are not going to attract any deaf people. If you are going to talk about discrimination, let us start at home.

QUESTION: Judy, I hear more and more about drug addicts and

alcoholics identifying themselves as disabled people. Could you comment on this?

MS. HEUMANN: I will repeat what I stated earlier. I believe first of all that persons who are substance abusers or drug addicts or alcoholics are disabled individuals and in many cases have multiple disabilities as a result of their substance abuse. Phyllis Rubenfeld referred earlier to physically disabled individuals saying, "I'm not mentally retarded"; we also shout, "I'm not a substance abuser," because there is an additional stigma attached to persons who use drugs or alcohol excessively. However, I would like you all to recognize the fact that in California the problem of substance abuse among disabled individuals is at epidemic level. I believe this is a problem that we as disabled individuals need to examine very thoroughly, because excessive drug use and excessive alcohol use is a political way of maintaining oppression within a group of persons. What is going on within the disabled community is that the medical profession is legally prescribing medication for persons who are disabled. Persons who have spinal cord injuries, newly disabled individuals who come in and talk about having pain and spasms or being nervous or whatever are given drugs because the doctors do not know how else to deal with these complaints. One of the things that we did during the 504 demonstrations in San Francisco last year was to actively encourage organizations that represented persons who were drug addicts and alcoholics to come and work with us, because we need to broaden our base. We need to have as many people as possible in the broad class of disabled individuals working together, not as few people as possible. We need to recognize that we are discriminating against parts of our group because of the additional stigma that has been forced upon them. They are a part of our family and I welcome them.



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Attitudes toward the Disabled

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I hope that what I have to say will leave you thinking and talking. I know from past experience that some of you will be more annoyed and angered by what I have to say than in agreement with me. I will be talking about several aspects of attitudes toward disabled persons and about social interaction between disabled and nondisabled persons.

Let me start out by making a distinction that I feel is quite important, a distinction between a disability and a handicap. Many people use the two words interchangeably. I do not. To me a disability is a physical or mental condition. It is a characteristic of a person. People have disabilities. A handicap, on the other hand, is—and I quote from *Webster's Collegiate Dictionary*, with which I am sure you are all familiar—"a disadvantage that makes achievement unusually difficult." A handicap, from my point of view, is often a characteristic of the environment rather than of the individual, and those of you who are psychologists will be aware that one of the great psychologists, Kurt Lewin, said that behavior is the function of a person in an environment. The person may have the disability but the environment produces the handicap. I am also interested in the fact that the term "handicap" is very often used these days with regard to horse racing. In horse racing, when they handicap horses, they put extra weight on their backs so that they cannot run as fast. I find this a very useful analogy because, as I see it, a handicap is a weight on a person's back that makes it more difficult for that person to compete. And as I like to point out to my friends, in horse racing they always handicap the best horses. I let them draw their own conclusions. Incidentally, I do not like the word that is occasionally used, most notoriously at Michigan State University, referring to disabled people as "handicappers"—this seems a singularly bad choice of words.

Now, let me talk briefly about equal opportunity and affirmative action. Equal opportunity is very much emphasized these days. It can be defined in many ways. To me it means the removal of handicaps. Handicaps inhibit full participation in society; they can be removed. Disabilities are very difficult to change. Handicaps can be changed. In the United States we presumably believe that all men are created equal, which of course should be amended to read that all persons are

created equal. While this is a nice-sounding phrase, as far as I am concerned it is nonsense. We are not all created equal, and I personally am very glad that we are not. But this is not the crucial matter. To me the crucial point is that all men and all women are entitled to equal opportunity and equal treatment under the law. How equal they were created is comparatively unimportant from this point of view. Equal opportunity results in useful, productive interaction between disabled persons and nondisabled persons. Speaking as a social psychologist, it is this kind of interaction that usually results in liking and in positive attitudes.

Handicaps can be divided somewhat arbitrarily into two categories. There are physical handicaps and there are psychological handicaps. The physical handicaps generally involve such things as accessibility and communication. I am continually disturbed by the lack of accessibility, to the disabled, of all kinds of buildings—housing, schools, educational facilities, recreational facilities, stores, doctors' and dentists' offices, public buildings—even hospitals are not accessible, and public transportation is worst of all. This is really a major problem for our country.

Even at a place like Hofstra University, where we started a program in about 1963 to make the place accessible, we are only 90% accessible, and we are still trying to get the other 10%. Incidentally, if you are an optimist as I am, you can draw some comfort from all this. It was pointed out to me a while ago that lack of accessibility guarantees that disabled persons will never go to hell—because it involves going down a flight of steps.

These, then, are the physical handicaps. What about the psychological handicaps, the handicaps relating to attitudes? To me these are the most important handicaps, the most important barriers. These too can be divided into categories. Some attitudinal handicaps derive from the attitudes of disabled persons toward themselves. Some people with disabilities carry great weights on their backs, such as their attitude toward themselves, their attitude toward other disabled people, and their attitude toward society. But in addition to the attitudes of the disabled individual, major handicaps are also provided by the attitudes of other people, who often perceive the handicapped person in ways that are very distinct and not very complimentary, to put it mildly.

I think a few words about positive and negative attitudes toward disabled persons might be in order. There has been a surprising amount of research on attitudes toward the disabled as expressed by nondisabled persons. Studies have shown that most persons express socially acceptable attitudes; that is, they say things about disabled persons that could be interpreted as reflecting positive, sympathetic attitudes toward them. But at the same time, if we dig a little deeper, we find indications that most nondisabled persons perceive disabled persons as being different. And very often in our society, to be different is not good. But not only are disabled persons perceived as being different,

they are perceived as being, in at least some ways, inferior. Feeling that someone is inferior to you may make you feel good, but it surely does not help the person whom you feel to be inferior. Very often nondisabled persons will be uncomfortable and will believe that they do not know how to behave in the company of disabled people. These attitudes often result in one or another kind of discrimination and prejudice with respect to the disabled individual.

What are positive attitudes toward the disabled? To me a positive attitude is one that reflects a lack of prejudice. A person with a positive attitude toward disability will react to a disabled person almost exactly the way he or she would react to a nondisabled person who exhibits the same behavior. A positive attitude means you are neither more friendly nor less friendly; you neither like the person more nor like the person less. You react to the individual as a person, not as a disabled person. You are influenced primarily by how the person behaves, not by stereotypes, not by prejudices, not by labels, not by ideals about how blind people are supposed to act or how people with infantile paralysis are supposed to act or how the deaf are supposed to act. I recently found myself in a bit of trouble because I expressed some extremely negative feelings toward a professional person who happened to be deaf. I was not reacting to the deafness, I was reacting to the fact that the person was quite incompetent, and I emphasized this. I was told, "You really shouldn't criticize him, he's disabled." I said, "I don't care what he is he's incompetent and that takes priority." And this to me is a crucial point. A person who has positive attitudes toward the disabled will believe that disabled people should be judged by the same standards as nondisabled people.

I am not trying to ignore the disability. I am pleased when in bad weather, when there is ice on the ground, one of my friends grabs my arm; it is very helpful to me. I do not want people to ignore the disability in that sense. But in most aspects of my life the disability is not very important and I expect it to be ignored. A person with positive attitudes will have very positive feelings about those disabled people who behave in ways that they approve of and very negative feelings about those disabled people who behave in ways that they disapprove of.

One of the things I am saying here is that you cannot say anything about all disabled people or about all people with a particular kind of disability. You do not know them. When Hofstra first started having people in wheelchairs on campus, I would get requests to talk to groups of students and faculty as the resident expert. What it came down to was that the nondisabled who were very interested and wanted to be useful and helpful all had what amounted to the same question: "How do you behave toward disabled people?" And my answer was, "I do not know." In essence they said, "Suppose you are walking along and you see someone in a wheelchair. Should you offer to help them?" And I said, "I do not know that either." And they said, "Well, what

should we do?" And I said, "Well, if it bothers you, ask the person if they want to be helped and they will tell you. Some of them do and some of them do not." And at this point I tell my story about two students at Hofstra. One was a very attractive, slim, blond young lady in a wheelchair, whose basic attitude was "I'll do it myself, Mother." She wanted no help whatsoever under any conditions. We would see Ruthie struggling up a ramp; but everyone knew, not to offer to help her under any conditions. She did it her way and did it very effectively. On the other hand we had John who was a GI veteran. Whenever he came to a ramp he would ask for help. But first he would look around to see if there was an attractive young lady that he could ask. John played on the wheelchair basketball team; he was stronger than any three nondisabled guys on campus. But he knew a good thing when he saw one. Now, what can you say? There is no single answer to this. For my part, I think one of my sensitivities is that I overreact to some people who say, "Isn't it great what you have achieved, even though you are disabled." I think that is nonsense. I have run into prejudice, every one of us has.

When you meet a person for the first time, you tend to make very quick judgments regarding the individual's physical attractiveness, personality, friendliness, confidence, and so forth. The presence of disabilities can influence how people perceive physical attractiveness and how they perceive confidence. But it does not have to. We can dissociate these things. Furthermore, the disabled person can do a great deal to influence how he or she is perceived by changing their personality to be more attractive, more friendly, and so forth. This makes a great deal of difference.

Let us now consider interaction. One thing that has a crucial influence on attitudes toward the disabled is how much experience an individual has had in interacting with disabled persons. Some people have experiences with disabled persons that lead to positive attitudes. Other people have experiences that lead to negative attitudes. Research has indicated that certain factors are very effective in bringing about positive attitudes. And I would like to list briefly for you some of the factors that lead to "good" attitudes toward the disabled. First, and very important, is frequency of interaction. Usually, the more often the person comes in contact with disabled people, the more positive will be that individual's attitudes. Data supports this, and it is an extension of a fascinating thesis first formulated about twenty-five years ago by a sociologist named Homans. Homans said that the more you interact with people, the more you will like them. While it sounds over-simplified, there is a lot to be said for that hypothesis. And I can indicate why. The more you interact with a person, the more attractive does that individual appear. Physical appearance matters a great deal the first or second time people interact. After that, it is less important. Studies of dating indicate this very clearly. When you choose a date for the first time, you (and by "you" I mean both men and women) pick

people who are physically attractive. Once you know your date, other factors begin to be much more important. Second, the more you interact with a person, the more do the positive features of the personality become apparent. You see the good things. Now obviously, if your interaction with the person takes the form of constant fights and disagreements, this does not happen; but in general that is rather unusual. Third, and very important, the more you interact with a person, the more likely you are to perceive his or her abilities and competencies, rather than the disabilities and the incompetencies. The emphasis should always be, as far as I am concerned, on ability and not on disability. You all know the old question, "Is the glass half full or half empty?" As far as I am concerned, every human being has some abilities and some disabilities, and we get along much better if we focus on the abilities rather than on the disabilities. And fourth, the more you interact with a person, the less obvious the disability becomes, so that in time you do not notice it anymore.

In interaction, another factor that is important is the relative status of the persons. If an individual is interacting with someone who is of either equal or higher status, attitudes tend to be positive. If a person is interacting with someone of lower status, attitudes very often tend to be negative. It does not help if your interaction is with a disabled person panhandling in the Times Square area. It does help if your interaction is with a disabled professor teaching in a class of regular students. It does help when we have a president with a disability, as was Franklin Roosevelt. Incidentally, you can tell times have changed if you are as old as I am and you remember that when Roosevelt was in the White House his disability was almost never mentioned. You never saw him in a wheelchair. Whereas on television a couple of months ago he was shown in a wheelchair and his disability was very apparent. I thought that was great. Because here was a man who was competent and who was finally being shown as disabled.

Status makes a great deal of difference. For example, I unabashedly make use of the fact that I several years back got a Ph.D. (Incidentally, I am very pleased that my thesis adviser is now teaching at Teachers College and is in this room at the moment.) Getting the Ph.D. has meant a great deal to me, not only because of the work, the recognition, and so forth but because it has enabled me to use the title. I know, for example, that if I walk into a restaurant by myself with my funny walk and ask for a table, I get very funny looks and sometimes I get a table and very often I get no table; if I do, I get a bad one and so forth. So the easy way is to call up first and say, "This is Dr. Yuker and I would like to reserve a table for one person." And they lay out the red carpet, you see, and I get a good table. They do not know that I am not an M. D. who gives very big tips; I get good treatment. Status makes a difference. Status lowers barriers. The fact that I am a guest speaker means that it was a lot easier for me to get here than it was for you. We parked the car right outside the building

as a result of status. So it can make a difference. Status is important.

Incidentally, and I do not have time to go into this in detail, status accounts for a lot of problems that occur in the hospitals and rehabilitation centers. Studies have shown that doctors, nurses, and workers in rehabilitation centers and hospitals often do not have positive attitudes toward disabled people. You would expect them to, but they do not, by my definition. Why do they not? Because disabled people are seen as having much lower status: they are incompetent; they are there to be helped. And if you are helping someone you look down upon them. Apparently this accounts for at least part of it, and I know I am oversimplifying.

Another factor is the type of interaction. Friendly, cooperative interaction results in positive attitudes. Competitive interaction usually results in negative attitudes Incidentally, one of the things that does not work is to get people together and say, "Okay, some of you are disabled and some of you are not, now let's get together and try to become friends and try to like one another." It just does not work. When people are getting together to tackle a common problem, that works. But just to call them together and say "let's be friends" does not.

The perceived normality of the disabled person is also very important. Some situations tend to emphasize disability. Others tend to emphasize normality. This can make a difference. The extent to which the disabled person is seen as being able to cope differs from one situation to another. Sometimes it is very easy. I have problems at cocktail parties. I have found that when I am at a party where I am tense, where the people do not know me, the best thing is not to have a cocktail because my way of drinking might call attention to my disability, and this is better avoided. Again, you might disagree with that particular solution.

I have two additional points I would like to make. The first is what I call the rule of circularity, which says: If the disabled person ignores his or her disability most other people will; and if the disabled person cannot ignore it, other people will not. I find it interesting to categorize disabled people with regard to the percentage of the time they perceive themselves as being disabled. I think I am aware of my disability on an average of 5% to 10% of the time. Most of the time I am too busy being this, that, or the other thing to be disabled. On the other hand, I know some people who make a profession out of their disability, and they see themselves as disabled 80% of the time. They have a rough time of it as far as I am concerned. You get circularity, generally.

The other point is that the setting in which the interaction occurs is very, very important. If you interact in a setting that emphasizes equal status, working toward a problem, you find positive attitudes. If you interact in a hospital or even a conference such as this, I do not think it evokes positive attitudes to nearly the same extent.

Finally, I would like to mention two personal goals—not for

myself, but for our society. I think they are goals I try to work for. The first is to try to change attitudes so that all people have equal opportunities, and that is not easy. The second is to try to help our society to provide opportunities for social interaction so that people of all races, creeds, and physical conditions can get to know one another and get to like one another.

PANEL DISCUSSION

Panelists: Adrienne Asch, Teachers College
William Langner, Cordet Center
Richard Shaner, Blinded Veterans Association
Erik Widder, Living with Cancer, Inc.

Moderator: Bette Knapp, Mainstream Inc., Riverside Church

QUESTION: Has Dr. Yuker's work on campus with the physically handicapped students and the fact that he has a Ph.D. helped his status vis-à-vis other faculty members in discussing issues concerning handicapped students?

DR. YUKER: I think the fact of having the Ph.D. is probably very important. College professors, like other human beings, are status conscious, and this makes it clear that I am their equal, because almost all of them have a Ph.D. These days on college campuses, the person without a doctorate is seen as having lower status and is treated accordingly. I will say however that probably the fact that I now am provost and am perceived as having power gives me a little more influence than I had when I was just another member of the faculty.

QUESTION: The point is that not everyone has a Ph.D.; what about the disabled person without it?

DR. YUKER: Let me say that I emphasize a doctoral degree, probably overemphasize it. There are many other ways to achieve status. One of the best ways of acquiring status is to do something well. Whatever it is, do it well. Anyone who takes on something and does it well shows that he or she is competent and achieves status through that. It may not help you get a table at a restaurant, but there are other ways of doing that.

QUESTION: I cannot tell if a person has dealt with his disability if he has overridden it with status. The disability is still there.

DR. YUKER: The disability is still there but I would say that the handicap is not. I am a strong believer in what Max Weber called the Protestant ethic, the work ethic. We were talking about emphasizing abilities, emphasizing competence. I believe that everybody can develop

their abilities, can develop their competencies, and this is what I am trying to urge.

QUESTION: My question refers to the reactions of professors when I intercede as a counselor for the handicapped. It seems to me some people think having a counselor for the handicapped is a bit unfair.

DR. YUKER: My attitude is—and I know you will not like this, but I am going to say it—my attitude is that we should make it possible for the handicapped to get on campus but the counseling is something else. I believe that once they are there, they should be treated like everyone else.

QUESTION: You said that a conference such as this does not evoke positive interaction. What is your reason for that?

DR. YUKER: Because it makes people sensitive to the disability. It is not completely relaxed; we are not interacting one to one.

QUESTION: Should not college professors have more training and knowledge about disabilities, more sensitivity toward disabled individuals?

DR. YUKER: It is a real problem, but I doubt if you will ever get college professors to sit for a day of lectures on understanding the disabled, much less attend a workshop for two or three days. It is up to us, the disabled, to educate our professors.

QUESTION: I think you overemphasize the question of status. In a place like New York, status is not that important.

DR. YUKER: Your point is very well taken. The reason I emphasize status is that despite what we may think about our society, all the research indicates that most people are very status conscious, they react to status. But I agree you are much better off in a cosmopolitan place such as New York City than you might be in a smaller place, where status might be more emphasized.

QUESTION: I do not think that calling attention to one's disability is the problem. What we should try to do is deemphasize the stigma.

DR. YUKER: Again, I disagree with you. I am speaking here on the basis of what social psychologists have found out, namely, that people who are different, people who are perceived as being different, are usually perceived as "them" and not "us." An anthropologist named Clyde Kluckhohn and a psychologist named Henry Murray, pointed out in a book written in the early 1950s that all men are in some ways

like all other men, in some ways like some other men, and in some ways like no other men. A very good statement. The point is, are we going to emphasize the ways in which we are different from others? If we do, then the stigma becomes part of it. If we emphasize our similarities and deemphasize the differences, there is no stigma.

QUESTION: I know Ph.D.'s who cannot get jobs. But plenty of panhandlers get by.

DR. YUKER: I do not accept that statement any more than I accept that anyone has to be a panhandler. I reject that completely. I am an optimist. When I speak about the difference between people's reactions to the disabled panhandler and to the disabled Ph.D., some of you react with hostility because you feel I am saying how great I am. That is not my intention. I am telling you the results of research. Ask people how they react, and they will tell you they look down on panhandlers and they look up to Ph.D.'s. I am not saying it is justified; I know some pretty ineffective Ph.D.'s. Incidentaliy, I know some very, very friendly panhandlers, but I sure would hate to have my kids learn from them. I am sorry, I have to leave the discussion now. Let me repeat, I wanted to present some ideas. I told you when I started that some of you would not agree with me, so at least you have to say that my perception was accurate.

MS. KNAPP: Most of my life has been spent in the area of political science and international relations. I was executive director of the World Affairs Center in Hartford, Connecticut, for twelve years, and this meant all types of community activity, working with people—all kinds of people, from junior high school youngsters all the way up to senior corporation executives—leading tours to Europe, and doing various other things. Then I came back to Columbia to try to finish a Ph. D., and various things happened during that time. I became interested in the whole civil rights movement of persons with disabilities and started, at Riverside Church, this task force on attitudinal and environmental barriers. Mainstream, Inc., is the first group to work through the churches and with the national denominations on this issue. My own disability was juvenile rheumatoid arthritis, which started when I was three and a half years old, so I have spent a good part of my life in a wheelchair—since I was about six. Incidentally, there may be some among the chair users here who are in my age category; but the younger people probably do not realize that these wheelchairs are really a revolution in the whole movement of disabled people and their integration into society. When I was a youngster all I had was a folding auditorium chair with four little tricycle wheels attached to it—and that is all that was available pretty well up to the time I went to college.

MR. WIDDER: I am a student at Brooklyn College. My disability is far from obvious; I have cancer or, more specifically, Hodgkin's disease. I was diagnosed as having it about five years ago, just after I graduated from high school. Subsequently I began studies at Brooklyn College, and now I will be graduating this June and going on to graduate study. Fortunately I have come across a new nonprofit organization, Living with Cancer, which is composed in part of young people who have cancer; they are sensitive to the needs of young people with cancer, and are beginning to do things to help themselves. It is through Living with Cancer that I am here today. Basically, I am here as a student with a disability.

MR. SHANER: Being with the Blinded Veterans Association and the field service program means that I spend about half of my time out on the road. My basic function is to make contact with the blinded veteran and introduce him to all the resources that are available in his community through the Veterans Administration. But I look on my being out in the field a little bit differently, and it fits in quite well with what we have been talking about today. Every time I take a train, take a plane, or go to a hotel, I am helping with the overall educational process and breaking down those attitudinal barriers. I consider—and this is my own private little secret—I consider this to be my primary function on the road. I am a former marine, a college graduate; I have had a little bit of teaching experience and done two years of counseling.

MS. ASCH: I am experiencing status disequilibrium or something of that sort. When I walked in here to join this panel, I found that the person who chairs my department was here, since he was also Dr. Yuker's thesis adviser, as Dr. Yuker mentioned. I found myself enormously embarrased and not quite prepared to merge my roles—as a disabilities activist and as a budding social psychologist. I am not sure how these roles fit together; I hope I will be successful in blending them. I will try to comment both on Dr. Yuker's presentation and on his research on attitudes toward the disabled, especially as these are affected by laws and political movements.

MS. KNAPP: I wonder if I could exercise the authority of the chair and ask if each one of you, in making your comments, would also react to the statement about the setting in which interaction occurs—the importance of the setting, how we find appropriate settings, and so forth.

MR. WIDDER: I suppose first of all I might address the issue of the attitudes people have toward individuals with disabilities. I suspect that most people would not think that someone with cancer would be on this panel, would not see someone with cancer as being a disabled person. Basically, that is because we are a new segment of the disabled

population. Before adequate treatment was available, we just were not around. So we are a new category of disabled. Now, one of the things that causes difficulty, as any disabled person knows, is that people generally have stereotyped ideas about people with disabilities, and these stereotypes must be confronted and dealt with. The stereotype people have of someone with cancer is deterioration and death, and that is a very difficult stereotype to confront. Most people are afraid of cancer; they have personal fears about it. If I had a heart problem or some other disease threatening my life, people would not experience quite the shock they do when they find out I have cancer. So dealing with that stereotype is particularly difficult.

For people with cancer, the psychological problems are probably the most difficult of all. In terms of the personal attitudes that individuals have about themselves and how they relate to their dealings with other people, people with cancer are usually just as naive as anyone else. When they first become ill, they have the same stereotype about the illness–deterioration and death. And that, too, is something very difficult for people with cancer to deal with. Also, we usually do not know what our limitations are. Once we have gotten across the obstacle of dealing with the uncertainty of our lives and with the problems we are facing, we want to go out and socialize. We finally realize that yes, we are alive and we are going to have to face these issues about the quality of our life. But we do not know what our limitations are. Our disability is not a stable one. A person with cancer can do quite well for a while, then have a relapse and have more trouble, then do better again and make improvmeents, then run into more trouble. He does not know where he stands. That also is a problem peculiar to people who have cancer. Socially, since this is a topic we are discussing, I know that I might be very motivated to increase my relationships, to go out and not remain isolated. Then I may become ill and have some complication that will interfere physically, and most of all psychologically, with my going out and being sociable, and I will just break off contacts. And there I am having to start the battle all over again. My limitations are not clearly defined, and I, as well as the people who have stereotypes about me, am confused about what having cancer means–what it means to me, how it influences my life.

In terms of social setting, I think it is significant that having cancer is not a visible disability, or at least in many cases it is not, so most of the people I deal with do not know that I have cancer. At first thought that would seem to be a great asset when compared to disabilities that are visible. But on the other hand, it is a barrier between me and other people. I cannot let them come too close because I have something to hide. I have a great secret–that I am disabled or have a disability (there is a distinction–and preserving that secret keeps me from forming close relationships; it keeps me in only superficial contact with other people.

MR. SHANER: Well, I have one of three choices. I can disagree with

Dr. Yuker and make some friends out there or I can agree with him and get tarred and feathered, I think. Or I can do what I intend to do, hedge. I think–and this is my honest assessment and reaction to what Dr. Yuker has said–I believe status is as important to me as it is to him. Panhandlers are not a good example. But let us just say that disabled persons who are not successful, that is, not as successful as, say, Dr. Yuker, do not turn me off as badly, because I realize that everyone has their limitations. I believe in working up to your potential, but I think it is important to be realistic and realize that people do not all have equal potential.

As I said before, we are all, every one of us who has a disability, personally liable for educating the public. It is so important; I so often see the need. Being blind, I get my cues much more quickly in some instances than those who have other disabilities. The very first cue that reaches out and grabs a blind person is the other person, literally. If I am standing at a street corner and someone grabs my arm, I know here is a guy I have to work on. I might not even want to cross that street, and before I know it I am halfway across. My cues come quickly.

Attitudinal barriers are there, we all know it. How do we break them down? By individually, independently breaking them down. It has to be one at a time, and I believe in that old adage about honey will draw more flies than vinegar, so I do not believe that belligerence is the answer. For instance, when someone grabs my arm and wants to drag me across the street, I do not push the person away and say, "Leave me alone. Why did you do that?" I try my best in those five or ten seconds to point out that what they did was incorrect, that there is a better way; and we get along just fine if they do it the correct way. My closing comment, not so much a response to what Dr. Yuker said, but my own independent thought: The more we have to legislate to enable disabled people to do the everyday things in life, the more ignorant we portray our society as being.

MS. ASCH: Mr. Shaner just said that the more we have to legislate the more ignorant we portray our society as being. I neither agree nor disagree with that statement. I do not really care if our society comes off as seeming ignorant. Perhaps I would not have used that word. I think the fact is that without legislation and without vigorous enforcement of that legislation and without promulgating even more legislation, we are going to have fewer disabled persons accomplishing what they would like to accomplsih. Why do I say that? It is strange that not just Harold Yuker, but several of the other distinguished lecturers and other panelists and lots of other people in this room–and lots of people out of this room whom we could name–have worked very hard and fought very hard, fought their own independent battles to change other peoples' attitudes and win the right to do what they were competent to do. We are all fighting, and all the laws in the world are not going to change the fact that we each independently have to fight a

certain kind of fight—including getting the people who grab our arms to stop grabbing our arms to take us across streets. There are plenty of independent battles left to fight. All the laws will not prevent us from fighting all the independent battles we would like to fight. There will be more than we can ever fight.

I travel a lot too, both around New York and around the country, and as a blind person I also have to deal with the sighted public grabbing my arm and screaming at me and doing various other things. In order just to go about my daily routine, I have to do a certain amount of educating or else I am not going to get my business done. I do not consider that a privilege, I consider it a nuisance, and I think it should be recognized for what it is. It is a nuisance. It would be much more pleasant if I did not have to spend time doing that in order to get my business done. I would get places a lot faster. However, if it changes people's attitudes, fine, I would like it to, and I would like to do what I have to do in the least belligerent way possible—although there are people who would accuse me of being the most belligerent person they know.

That brings me to the question of what belligerence is. If fighting for one's rights is belligerent, then I am belligerent and proud of it. I hope I never stop. And I hope that more people start. Dr. Yuker is not here for me to pose the question of whether attitudes must change before laws change or whether laws can be instrumental in getting us into the settings where frequent, cooperative, common-problem kinds of relationships can develop. I think that what is really important is to realize that some attitudes have changed, otherwise certain laws would not have been passed and signed and to some degree, halting though it may be, implemented. But there are a lot more attitudes that need to be changed—attitudes of the implementers, the legislators, the employers, the educational institutions, the people in restaurants who are impressed by one person's status.

There is another weapon that Dr. Yuker and all of us have—not our status but the law. In the state of New York, let us be very clear, you cannot be discriminated against in a restaurant, regardless of your disability. You have a law to use and I hope you all use it. It is the Human Rights Law of the State of New York. Denial of service in restaurants or health clubs or movie theaters or trains or buses or whatever—if you can get on the trains or buses—is a denial of the right to a place of public accommodation, and we have that right guaranteed by state law in the same way that other minorities have that right. I would urge you to use it. Whether attitudes change or not, we still have that right. Hopefully, those attitudes will change as we go about our business and do more of it.

Dr. Yuker talked about the setting for social interaction and I was asked to comment on it. I have already made clear that I think law can be an instrument for getting us into those settings—whether restaurants or work places or social organizations or educational settings. But there

is another setting for interaction, and that is the setting that we as disabled people have to create for ourselves. I do not mean a segregated social club born of a sense of disappointment and depression and a feeling that we are not wanted elsewhere. I mean the setting provided by a strong, unified political–and I mean political–organization to achieve what we are entitled to as citizens in this country. It would have been very nice if women and other minority group members could have achieved their rights without banding together, but they did not do very well at it; and we have not done very well at it without banding together. I think it is high time we all took steps to band together in groups–as the American Coalition of Citizens with Disabilities and other groups have done. Living with Cancer, whatever the extent of its political activity (and I do not happen to know) is important both as a self-help and as an advocacy group. I do not think that being in a setting where we are dealing with other disabled people is any slur on our desire to be integrated into this society or demeans our attempts in any way; it is in fact the way to achieve our goals. So, I think that we should understand that self-help organizations, and projects for disabled students, can be means to ends–to social integration, to economic integration, to power for the disabled; they do not have to be settings of isolation and negativeness.

I want to talk about one other thing, the kinds of positive attitudes that Dr. Yuker was discussing. I felt as I was listening to him that I was hearing myself ten years ago and hearing blacks who had made it, women who had made it ten, fifteen, twenty years ago–basically a statement of trying to be as invisible as possible, to be accepted on the nondisabled person's terms. Avoid having a drink at a cocktail party because it is going to call attention to your disability. Now the fact is that if I am honest–and I will try to be honest–I know that I use some of those same rules to guide myself; that is, I want to appear in the best light I can in new situations–as we all do, disabled or not. I am sure that I avoid doing certain things in new situations that I might be more comfortable doing where people know me. But I am not sure that is such a great thing. I think it is unfortunate. It is my realistic assessment that when I go into a new situation one of the things I have to deal with is being accepted. I have to gain acceptance for my personality–my abrasiveness or my lack of abrasiveness or my shyness or whatever–and my blindness. And I know that my blindness is going to dominate the initial set of reactions. So, I am sure that I try to do things to help people get over that issue quickly. While I know that this is true, I do not applaud it. It is my method of getting through and getting to the more personal social interaction I want. And the only reason that it is done by disabled people is to get to that further, or better point. If we were not living in a society where how we handle drinks at cocktail parties or move around unfamiliar rooms is taken as a sign of our competence, we would not have to go through all those machinations. I do not applaud this, and I do not suggest that we try to perpetuate the

ways in which we have to work so hard to function on everybody else's terms—to hide, to be invisible, to pass, to be as little disabled as possible. I do not mean that we should think of ourselves as disabled 100% of the time; but constant concern about whether our disabilities are visible or invisible affects how we do certain things.

We can have a positive and realistic attitude that is not acceptance of hiding but is also not flaunting, is not anything; it is saying that we are, as Dr. Yuker stated, in some ways the same as all people, in some ways the same as some people, and in some ways different from other people. And that is true of all of us, disabled or not. Our disabilities may make us different from some of the people we know. But different does not have to mean inferior; it should or could mean just different. Dr. Yuker spoke about an attitude that we all live with in one way or another, an attitude which says that anything that is different is bad. Difference is so little tolerated in this society that the whole name of the game is to be as much the same as everyone else as possible.

Some of the research that has been done by Dr. Yuker, which he did not really talk about in detail, was a scale that he and some other people developed called the Attitudes toward Disabled Persons Scale. I took a look at that scale. If the respondent answers—and this scale is administered to both disabled and nondisabled persons—"positively" to the items, he or she is assumed to have positive attitudes toward the disabled. I want to read you some of the items that I think are problematic and say why I think they are so. One we have already discussed: "Disabled persons are the same as everyone else." Another: "Most disabled people worry a great deal." Another: "Disabled people should not be expected to meet the same standards as nondisabled people." Another: "It is almost impossible for a severely disabled person to lead a normal life." Another: "Disabled people tend to keep to themselves much of the time." Another: "Most disabled people feel they are not as good as other people."

What do we think about these? I know that ten years ago if I had been asked to answer these questions I would have given all the "positive" answers. "Disabled people are the same as everybody else," I would have said. "Of course, disabled people should meet the same standards as nondisabled people." "What rubbish!" I would have said, "Of course, disabled people can have a normal life." But it is not true. And saying that it is not true does not mean that I have a set of negative, self-hating attitudes. I may, but they are not going to be revealed by this scale. Why? Because this scale blends facts, stereotypes, environmental issues, and goodness knows what else. "Disabled people should not be expected to meet the same standards as nondisabled people." Well, it depends on the standards. I do not think I should be expected to read print. I am not going to succeed. I do think I can be expected to "read" and get a job done. It depends on what the standard is.

"It is almost impossible for a severely disabled person to lead a

normal life." In this society it *is* almost impossible. The fact that I say it is almost impossible does not mean that I think we could not or should not. But it does mean that there are a lot of problems in the way. That is what laws and political movements are about—changing those environmental issues. "Disabled people worry a lot." There is a lot to worry about. Are you going to get on the bus? When you go to a new place, are they going to let you in? Should you answer those horrible application questions, "Do you have a disability?" Those questions are now unlawful, but not everybody knows that. What do you do when you get those questions? How do you get people to write references for you? Should they say you are blind, should they say you are not blind, what should you do? There is a lot to worry about. It does not mean we have terrible attitudes about ourselves if we think about these things all the time or some of the time, as we try to live in this world.

MS. KNAPP: I would like to add one more thing. I agree a great deal with what Adrienne Asch has said, and I think a generational gap was evident during this presentation. Many of us can follow the evolution of this movement, as you can that of the women's movement and the black movement. There was a time when people had to make in society on society's terms. That is no longer the pattern. Our belief is that society must change. I think we have to begin to think how we can bring about those changes; perhaps not all of us will do it in the same way. Belligerence may not always be the answer, but assertiveness certainly is.

The other thing I would like to suggest is that in addition to what our speakers have said about needing to come together to build our own strength as disabled persons through legislation and so on, there is another side. If you are working for integration, how do you integrate and what do you integrate into? And how do you overcome the anxieties and the attitudes of the persons who are not disabled? There is legitimate concern on both sides. Anyone, disabled or not disabled, going into a new group and trying to make new friends, tries to find some common ground. That common ground is usually a common interest, and that may or may not be one's disability. I think that is something worth looking at and was perhaps an underlying comment that was not emphasized enough in what Dr. Yuker was saying. In other words, we should not just try to adapt and be like everybody else. We should find out what the commonalities are that we have with other people in order to establish friendships and relationships with them, whether they be disabled or nondisabled. I would like to open this up now for questions and comments from the floor.

QUESTION: Working for the Mayor's Office, one thing I have found is that we are all people, regardless of disability. We all have the same foibles and the same problems.

MS. KNAPP: As different as we all are, we are still the same in many ways; we have to find the ways in which we are alike, the things that we have in common.

QUESTION: Research indicates that people react to the superficial appearances of others. Does that mean we should try to look like others? Should I wear a wig because I am bald?

MR. WIDDER: Regarding the issue of status, which seems to have elicited an emotional response from everybody, I think that research showing that status influences people's attitudes toward other people is not strange or something that even demands much research. People with disabilities are disadvantaged, competitively disadvantaged, and disadvantaged in the way other people view us. Status, because it elicits respect, is one way of compensating for that disadvantage, but it is not necessarily the only way. Changing people's stereotypes and views about disabled people is another way. I think it all revolves around the way people see us, and one way to change the way people see us is through status. Obviously, it is not the only way, but it is a way. I think that just the connection between status and respect, that simple thing, is the crux of what Dr. Yuker was saying.

MS. KNAPP: I had another reaction, and that was, "Don't let us sell ourselves short; disabled people can reach status as well as anyone else can." It may take a greater struggle, a bigger fight, but we can do it; and there are different kinds, different levels of status and different ways of attaining status. That is what I think he was probably saying, that we should look into it, not just pass it by and say, "Oh, no, that isn't for me, I am not capable of that." Because we are capable of that.

MS. ASCH: I guess I tend to take the stance of the political activist in these situations. That is part of who I am, and it is a part of what I believe is really important. I would be less than frank about things if I did not say that part of Dr. Yuker's point, part of Bette Knapp's point, is something that I also can agree with. We certainly should not, as disabled people or as anybody else, be satisfied to be less than we aspire to be. Gaining respect is certainly worth doing for our whole person. I am not for supporting collective action, using the law, or the political organization if that undercuts the pleasure we derive from our achievements as individuals and as a group. I think that the matter of setting and interaction is always going to be a matter of finding commonalities. The only reason to integrate into society, after all, is to become a part of those things and people you are interested in. I do not happen to be interested in going to Wall Street, so I do not really care if I go there or not; other people do. I am interested in going to places where I feel there are people I have something in common with, where I am not excluded on the basis of being disabled. It is finding

those commonalities that makes the whole political struggle worthwhile. It is only a struggle, after all, to achieve the things we want to achieve becasue we are not satisfied.

QUESTION: The lack of emphasis on organizing concerns me.

MR. SHANER: I could not agree with you more about the need to organize. The Blinded Veterans Association is not exactly what I would call a huge outfit, even though we do have, as near as we can estimate, about 60,000 blinded veterans in the country—not all of them service-connected cases of blindness. Our membership is not even one-tenth of that; and yet, just because we are organized and have very powerful and wealthy lobbyists down in D.C., we have a lot of influence. It did not come about overnight. A group of people got together after World War II and started the organization, and it has blossomed into one of the most powerful service organizations down in Washington, D.C. So organization is the key. Blinded veterans have a place to turn; they do not all know about us, but those who do have a place to turn. And I think that anyone with a disability should have a place to turn. The more people, the more clout you have down in D.C; that is where it counts.

MS. KNAPP: I too would like to affirm the organizational aspect. When I began to organize within the churches, some people looked at me as though I were out of my mind—why was I bothering with the churches? In 1975 I went to Nairobi to attend the World Council of Churches' fifth assembly. This was just when the whole civil rights movement was emerging both here and in Europe, and the agenda was very liberation-oriented. But the handicapped were not on it. I managed to get the question on the agenda and to get a very good statement out. As a result, five of the denominations in this country now have nationally adopted statements and task forces of persons with disabilities. Organizing entails a strategy of finding a place to set a precedent, getting people out. We are finding that people are working ecumenically, interdenominationally on this. Disabled people who are perhaps not the more activist types but feel very strongly about the fact that churches are not accessible are now rallying, because they have a rallying point, an organization to attach themselves to. So, I think that whatever field you are in, whatever ways you are able to organize, it is important to tie into something bigger, such as the American Coalition.

MR. WIDDER: There are organizations that were established to help people with cancer. But organizations of young people with cancer helping themselves, fostering their own interests—I think that is something very new. And I think it is something very important. Through organization one gains strength politically, and I think it also helps

the individuals who are organized. Just being a member of an organization that is working for your interests improves your own life as a disabled person. It enables you to feel productive, not only for yourself but for your peers in similar circumstances. For people with disabilities, I think membership in an organization is as useful as the organization itself.

MS. KNAPP: To what extent are any of you involved in either campus organizations or community organizations that tie into the whole civil rights movement?

QUESTION: I am part of the Hunter College Disabled Student Organization, which started about three years ago. We have not been able to command a lot, but if we had not organized, we would not have gotten anything. Students were told, "It's up to you." If we do not support each other, certainly the administration is not going to do anything.

QUESTION: I am a career counselor. Recently we spoke to some high school students about Section 504. They did not know their rights or about the organizations available to them.

MS. ASCH: The last two comments illustrate what I want to say. The first refers to a college that admitted disabled students but did not provide services. And we all know that some disabled students, with enormous effort, using their own resources, luck, and determination, do get through without such services. No one is saying that it cannot be done. People have done it and people can still do it. The second comment refers to an effort to inform disabled high school students about their rights under Section 504 and to make them aware that the situation in which they were living, their own school, did not fully meet accessibility standards. In that instance the principal was petitioned to do something about the situation. Those students were attending that high school in spite of the obstacles; they could have continued to do so. The point of organization is to get more of what many people manage to get on their own—many, but not all. Why should the benefits of this society consistently go only to the most determined, the most competent, the strongest, the wealthiest, the luckiest, the most enterprising? There is no reason why we should have to be better than everybody else to get what we want.

MS. KNAPP: Looking back on my own experience, I think this is part of what pushes me to do what I can to help bring about the changes that are necessary. I feel that timing is very important for anything of this kind, and that now is the time to do it. In my own experience, I went through schools that were never made to accommodate a wheelchair, although there were service elevators that I could use in several cases. But there was also the situation of being the first person in a

wheelchair, the only such person to enter any of the schools I attended. Even at Smith College it was, "If you can make it, fine, we'll let you in." I was turned down frankly by Wellesley (this shows you how far we have come in the last twenty-odd years) because the campus was too large and vast and I was told I would not be able to get around the whole campus in a wheelchair. I did not have to get around the whole campus, all I needed was one building that had an elevator. Mine is a case of somebody who could make it—who had a family willing to make the sacrifices, a family willing te help. My mother had to go with me; we could not afford to pay an attendant, and there was nobody else to do it. And no campus was really accessible. I know from my own experience what can be achieved. But you should not have to put that kind of investment into it. However, that is not to say that we were not happy.

Part Two

Education

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Liberal Education for the Handicapped

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What I am going to say is quite intentionally general, because I want to set up a framework within which you can raise specific questions that I have not touched on or that relate somehow to general observations I am going to make. So keep that in mind.

First, let me define my topic. A lot of people are struggling long and hard trying to define education, but I am going to content myself with simplicity. It seems to me that education can be divided into two kinds. The two refuse to stay separate, but for the sake of clarity I am going to pretend that they do.

The two kinds of education are vocational and liberal. Vocational education is the kind we take so that we can do something that we could not do before because we did not know how. An example would be learning to saw a board at a 90-degree angle—90 degrees from the beginning to the end of the cut, and 90 degrees from the top to the bottom. Although I have sawed many a board in my day, I still cannot make that perfect cut. When I do, it is by accident; and as you probably know, good accidents do not happen very often. If I were a carpenter and not in literature, I would have learned the skill of making that kind of cut plus a whole lot of other cuts. That kind of knowledge is very practical, because with it a person can make a chair, patch a roof to keep the rain out, etc. If I were really good at that sort of thing, I could hire myself out to do those things for somebody else, thus translating my knowledge and skill into money, which I could retranslate into a variety of other things.

The education of lawyers or doctors is equally vocational. They translate their education into practical use for hire, and they hire themselves out to patch kidneys instead of roofs or to serve as guides through the jungles of the law, and they do very handsomely for themselves in the process. In the use of their knowledge, they are no different from the carpenter or the bricklayer. To my way of thinking, then vocational education is the kind of education that the possessor *uses*—most often for making money. This is certainly the most popular kind of education, and it is going to become increasingly so. You may

be asking yourselves, "Is there actually any other kind of education?" If so, you may wonder of what value it is, if it is not practical and not translatable into cash?

Well, I think there is another. I call it liberal. And I even think it is the primary, most important kind, for reasons I shall try to explain. First, I must go back to the term "education." It comes from the Latin *ducere*—that is a verb meaning "to lead." And when you have the prefix *e-*, it means "to lead forth." That is probably nothing new to you. So "education" means an activity or a set of activities that have the effect of leading something forth from the student. But—leading what? That is the question. Well, leading forth the intellect and the emotional capacities of the learner; in short, his or her entire personality, enticing it out of its most secret retreats and challenging that personality to a sort of wrestling match, a full-scale struggle to understand and cope with all the complexities of being human. That struggle is immensely exciting and immensely stimulating and pleasurable as well and not merely to the intellectual faculties or the muscular skills but to the whole person. In other words, a liberal education does not offer the development of a marketable skill; rather, it promises the excitement of a full engagement with one's whole self, the reward being the pleasure of being more fully alive. Now, I know these are very abstract terms, but I am going to try to clarify them.

Traditionally, liberal education is confined in its definition to the study of philosophy, history, literature, subjects like that. But I do not believe that the terms "liberal" and "vocational"actually have anything to do with the subject matter of study. What determines whether a study or an activity is liberal or vocational lies entirely in the way the student feels about the subject. For instance, I could study philosophy with the specific purpose of making myself a teacher of philosophy so that I could make a living at it. For me, that study would be just as vocational as carpentry. Or, I can (and have) study for instance, automobile mechanics. I am no better as a mechanic than I am as a carpenter, as a matter of fact, so I only tinker around with my own car. I have reduced my garage bill, so there is some economic benefit for what little knowledge I have; but that is not the main reason why I inquired into the subject. I inquired into it because I was interested. Why an engine does or does not run actually fascinates me. A badly running outboard or car is a challenge to me; diagnosis of the problems forces me into a rigourous logical exercise that leads all of me forth, not just my mental faculties—I become desperately excited. When I occasionally find the cause of a problem, fix it, put things back together, step on the starter or pull the cord, no words can possibly express my joy when the thing runs.

Now, I have saved some money, which is nice. I need money, I like money, just as much as anybody else I know. But the pleasure that has streaked through me whenever I have dealt with one of those casual problems is not measurable in dollars and cents. So, mechanics is for me

a liberal pursuit, and what makes it liberal is the way I feel about it. It leads me forth, it invites me to grapple with complex reality, it taxes my faculties, my patience, and my intelligence, and it thrills me deeply. Do not try to hire me—I am not worth it. Besides I only work on engines for love, and love is just shorthand for those feelings I mentioned that consume me when my efforts prove to be successful.

But what does all this have to do with the subject I was asked to talk about? So far I have started by defining my key terms. Education is the main one, and I have said there are two kinds, the liberal and the vocational. And then I said the liberal is the more important, the more exciting kind. But my talk concerns education for the handicapped, so let us move on to the handicapped.

Now, to be handicapped simply means to be limited, not able to do everything. No human being is able to do everything, so to be human is to be limited. Most people, however, when they first meet me think that I am an oddity, because in addition to the usual set of human incapacities, I cannot see. I am stuck with that, or rather with both of those things. I am stuck both with my blindness and with other people's reaction to it. They are separate things, but combined they make a pretty marvelous mess to deal with. They constitute a rather special degree of limitation or handicap. Not too special, I know, when compared to others in this room. But special with regard to those so-called average or normal persons. I presume that in this audience, as in every audience, you can find the most wonderful collection of incapacities. I hope that perhaps you can see some relation between mine and yours.

I am not about to stand up here and ask you to believe the pious and heroic lie that my blindness has not been, is not now, and will not continue to be a most constant, profound, and infernal nuisance. To pretend that I have overcome it would be as foolish and dishonest as if I were to pretend to you that through great courage and moral virtue I have overcome the necessity to breathe. Just absurd. It was a fact, it is a fact, and it will continue to be a fact that because of my blindness I cannot, for instance, enjoy the beauty of the world at a distance. I do not know what my wife or my children look like. I cannot as my colleagues regularly do, which infuriates me, pick up a book and read it. I cannot gracefully pass the salt to a guest at my dinner table. I consider these serious and very terrible deprivations. What is worse is that they force me into a dependence on other people, and I resent those dependencies; but I have to learn to live with them as gracefully as I can, to accept them, as I must learn to live with the fact that I cannot watch the cardinal feeding its young in the nest just outside our bathroom window. So, my blindness causes me a lot of personal distress. Keep the word "personal" in mind.

As annoying as this distress is, it is not comparable to other people's conception of how blindness must limit me. I know through experience what some of these limitations are. They do not. But they

think they do. And this is what gives rise to most of the trouble. Since I cannot see, they assume that I am either sub or superhuman. Whether sub or super, the result for me is exactly the same. I cannot be communicated with. I am outside the pale. I do not belong. People separate me from the warm brotherhood of mankind, either by excessive pity or excessive admiration, and by either emotion they show that I am closed out of any possibility of ordinary relationships with them. In Paris, in London, in Sarajevo, in Stockholm, and in Watertown, New York, the waitress says to my companion, "Does he take sugar in his coffee?" If she were to think about it, which she does not (nobody does), she would have to explain that I seem to her like some marvelously trained dog, who has learned how to sit up and eat at the table and drink almost like a person, and can only be communicated with through my trainer. Now, am I angry? Yes. Is my anger a solution or a small step toward solving the problem? No. A joke might be, something or other that would suggest that I actually share lots of feelings with her. Something like "I like my coffee just exactly the way you like yours, Sweetie." Then maybe she might giggle and go on to say to my master, "Isn't he wonderful?" With the word "wonderful" she has flipped me over from the sub to the super. Which is no progress for me, but it is at least a change. She has flipped me into that same box, at the other end of the spectrum, into which I am tossed by prospective employers.

I have applied for teaching jobs in every respectable four-year institution in the United States—and some that are not even respectable. I have received all kinds of letters in reply. But when they start out with a compliment, I know what the end is going to be. I send off a description of my background, qualifications, publications, and all that, and the reply comes back with "Dear Mr. Russell, you're obviously just an amazing person. It's incredible what you've done. Yale, Oxford, those fellowships, won an international competition, all those books, those stories, those articles you've written, and all those years of chairmanship with that big English Department, why, you're just miraculous that's all. Just miraculous, that's all I can say. As to this job, we just don't see how you could possibly manage it, there are people to see, and well, we're just really sorry, we're sure you understand. With cordial admiration" and then the signature. Oh, I understand all right. Angry? Very. Solution? No more than with the waitress. Should I write back to this dean or president and point out the logical contradictions between his praise and his rejection? He is no dummy. He understands the contradictions as well as I do. He just does not want me around, that is all. And he does not because he thinks I am different. That would make him uneasy. Because it would make him and everybody else uneasy, it is more simple just to write me off. So, what might help? What might help is almost always impossible. What might help would be to get him out for a cup of coffee or a drink. Or lunch. To talk. In that talk we might get our ideas colliding, our values

engaging each with the other's, and at the end of an hour, maybe two, he might feel, "Yes, while there are differences, they are superficial. But more important, there are basic similarities—concerns that we share, sensibilities and attitudes. Above all, the things that we share are far more important than the differences that appear to separate us."

Do you recognize any of these things? This situation? If you do, then we can proceed with the subject that I am supposed to be discussing here. And that is, education for the handicapped. Remember what I said about education, the vocational and the liberal and the first aims of each? The first aim of the vocational is producing a marketable skill. The first aim of the liberal is the leading forth—it is an invitation, a challenge, to a kind of wrestling match with reality, a full engagement of personality. I said this second kind was most important for everybody. Now that I have defined the handicapped, I want to say that this kind of education, the liberal, is more important for the handicapped than for the "ordinary" person. I use myself as an example, and I hope you can see what I think my major problems are and that they have nothing to do with whether I am skillful as a carpenter or as a mechanic or as a teacher. My problems have nothing to do with whether I am good at my job. My main problem, and I think it is a peculiarly central problem for every handicapped person, is to convince the waitress and the college principal that we are human, that we are neither below nor above that classification, neither sub nor super.

If, for example, I were to bet all my marbles on carpentry and make myself the best carpenter in the world, that would not be any good if I could not get someone to hire me. My central and continual job is to calm those fears in the other, whether an employer or a waitress, that spring from his or her sense that I am an oddity. I have got to show others that I understand and care very much about the same basic concerns that fascinate and perplex all sensitive human beings. A liberal education stimulates precisely the kind of understanding and the kind of caring that holds the possibility of uniting all human beings. This sense of the the world communicates itself to other people and puts them at ease in one's presence. They no longer think of one as sub or super but simply as a person.

Too often we are inclined to confine the notion of education to schools and books, and this is really a disastrous restriction. It is unfortunate that we do this; because not only do we separate school from life, but we assume there is going to be no carry-over from books to living. And because we do not expect any carry-over there is none, or very little—which is too bad, since potentially there is a great deal. Let me tell you about a friend of mine who was, I will say, trying to get an education. Fred and I met at school for the blind in New York City. Fred had previously attended a public high school; I do not know if they are still in existence, but in those days there were Regent's—exams that you had to pass in order to get your high school diploma. Fred came to the school, the New York Institute, for what they called a year

of "postgraduate" work. When Fred came in he had passed all his Regent's, which most of us were in the process of trying to do. He was sporting a Regent's average of 94 or 95. So our impression was that Fred was pretty bright. One day I confessed, "Fred, I'm really impressed with your average in Regent's; mine isn't anything as good as that." And he said, "Don't be impressed, that doesn't mean a thing." I said, "Why doesn't it?" He said, "I took it at the public high school, and the teachers didn't know how to handle me. They couldn't give me the questions in braille, nor could they let me write out the answers in braille because if I had written them out they wouldn't have known how to read them. So they just read me the questions verbally, and when I couldn't tell them the answers, well, they told me; but it didn't mean that I learned anything. They were awfully nice to me, too nice to me, all the time. That's one thing I regret." The niceness of those teachers did not lead Fred forward. They did not invite him to engage with any subject matter. They, in fact, said with their actions—naturally they did not put it into words—something like this: "Fred, you're a poor blind boy and we know you've had a lot of suffering, so why don't you just stay there, secreted in your own person, and we'll deal with the problems of life for you. We'll give you the answers and you can just trot along. We'll take care of you. We'll shuffle you off to a sheltered workshop. You'll be all right, just don't worrry about it." That was not education although it happened in a school. They were actually holding Fred back, not inviting him forth. They were giving him neither a vocational nor a liberal education. They were asking him merely to serve time. That was a shame, because Fred had a lot to give, and he may in fact be giving it in ways that I do not know about. I have not been in touch with him in thirty-five years, but his story stands out because it spoke to me of the cruelty of kindness.

I desperately wanted to get out of that school. I wanted to go to college. I did not so much want to go to college as I wanted to enter a world where people could see, and I wanted to be accepted in that world. So I applied and was accepted at a college in upstate New York, a place called Hamilton College, a marvelous place, and I even got a scholarship. I did so abominably in my first semester that they took my scholarship away. I think I got four D's, as in "dog," and a D minus, as in "less-than-dog." I do not know what my average was, but it was appalling. No one had the guts to fail me. Yes they did, there was a marvelous chap in math, and he failed me. I respect him for it.

Academically, my freshman year was a bust. But my education did not suffer. At least in the sense of liberal education it did not suffer. I engaged in some very crucial activities that invited the wholeness of self out to an engagement with this new world in the middle of which I had landed. I learned how to drink beer. That mattered. That mattered desperately. I did not know it, I am not pretending that I was conscious of what I was doing, but the instinct of necessity drove me to learn these things. I played cards—poker, blackjack—long into the hours of

the morning with other wastrels and academic no-goods. I went to the gym. I had wrestled in school, and I wrestled in freshmen class the first day and pinned a sophomore that they had sent up against me. That did not hurt at all. It made me feel that I had to be dealt with, made them feel that I had to be dealt with.

The point is that while that first year was a great academic bust, educationally, liberal educationally, it was immensely important. I do not look upon it as a waste at all but as an exceedingly valuable time. Of course I made a fool of myself, with the excess of the young. That is the privilege of the young. But I needed to do that, and I had to do it there. I could not do it at the school for the blind; I did not need to do it there. It was not until my second year that I began to respond to academic subjects, to literature. I had to make my life in some way connected with books and reading. So that while I failed at Hamilton, academically, in my freshman year, educationally it was a great experience. It has continued to be that way throughout the years since that freshman year. I learned how to reach out to people. And all the important contacts of my life have been made not through the exchange of money but through the sharing of interests, liberal interests. That is, those interests that invite the coming forth of the whole person. Those interests that I pursue with others– sharing. This was and is and will be my liberal education. Sometimes these interests are and were academic, sometimes not. I have bent toward another and that other has bent toward me, over beer, over a dialogue of Plato's, over a cranky engine or a poem of Gerard Manley Hopkins, over a game of poker, a Beethoven quartet, the buzz of the reel when the fish strikes, the sound of waves, the feel of spray, a child crying in the night with no language but a cry–these interests and countless others have led me forth and challenged me to engage with another person, who, him- or herself, was tempted forth to engage with me at that point of our shared interest. And where we met, where we became friends, became lovers, was in the width of that foaming glass, at that word on the page, at that point in the cylinder where the spark did not flash to ignite the fuel, in that movement of the large, warm cello, that stepping down note by note from the cheerful major to the exquisite sadness of the minor.

Each of us nervous, uncertain what the other knew or felt, reluctant–each reluctant–to advance but still drawn forward by that thing between us, whatever that thing was. We came closer as if unable to help ourselves, the excitement about that thing growing all the time and our pleasure growing in the increasing closeness with the other; and then our meeting, always partial but always wonderful, and the parting, the withdrawal back to where each had been hiding, but never all the way back, not for each other any more, because each now felt relaxed with the other, comfortable in the closeness because each knew that the other was human too.

Since this is what I think happens, I suppose I ought to call this

kind of comfortable sharing of thoughts and feelings the product of a liberal education. But I do not like that idea of product, because it sounds too confining. It sounds as if now that it has happened, the education is over; and it is not, it goes on and on and on. There will always be marvelous books that I have not read. There will always be peculiar spasms in the outboard engine that I cannot figure out, that somebody will love to work on with me. There is actually an inexhaustible supply of fascinating people to meet as you actively pursue your liberal interests, whatever they may be. Now, "actively pursue" is obviously a key expression because it means going forth, energetically exercising your interest–all of you, not just your mind but your heart as well. In that going forth we entice others to do the same. This means we will meet others there, at that point. After meeting, through the engagement of personalities, we learn to accept each other as human. That is why I think liberal education is the most important kind for everyone but especially for us, the handicapped; because others who do not know us are inclined to exclude us from the club without thinking.

Once we can meet them, once we can make of them friends, the handicap, while it will never disappear, will take on its genuine significance–which is, very minimal.

PANEL DISCUSSION

Panelists: John Kemp, Kemp and Young, Inc.
Lorna McIntyre, Teachers College
Jim Reitwiesner, New Jersey Commission for the Blind

Contributors: Armand Bakalian, In Touch Networks, Inc.
Susan Beidel, St. John's University
Elizabeth Scott, Teachers College

QUESTION: I am rather disappointed that there are not more blind people in the audience. Why is that? Was this lecture announced on the "In Touch" radio program?

MR. BAKALIAN: I was not in charge of publicity. Perhaps I should have taken a little more initiative and contacted more organizations.

MR. RUSSELL: I did not mean to address myself only to blind people. I hope everyone in the audience found it worthwhile.

MR. KEMP: I would like first to react to one part of the lecture, the part about liberal education in conjunction with a college education. I, as a handicapped person, relate very well to that. I too had a bust first year, and not only that I had a bust second year. I enjoyed getting the liberal education more than I enjoyed the academic parts, but I had a lot of trouble persuading my dad about the significance of the liberal education I was receiving, the social advances that I was making,

the participation with other people, the socialization process. While my grades suffered, I relate very much to the feeling that there was an element of need and an element of success in spending my time doing that. I went to Georgetown University in Washington, D.C, where eighteen was the legal age for beer and white wine. I, too, had a great time learning how to drink, did a very good job of leaning how. It was very, very important for me to learn how to begin the process—of knowing women and men, of talking with women and men, of learning about areas of life beyond the mental ken of "I'm a handicapped person going to a big school for the first time." So I relate directly to what was said by Dr. Russell, and I feel that there is great value in urging that a liberal education be obtained by handicapped individuals.

QUESTION: During freshman year I went through a lot of the same experiences that you were talking about, and I did not go to class as much as I should have for that reason. I really relate to what you have said, because when I went off to college I was very short on socialization. Although my freshman year, and even my sophomore year, was as you might say an academic washout, I enjoyed it and I grew tremendously as a person. I learned to relate to people on an equal level, the way you were talking about, getting just as much from them as they were from me. I would not trade that for a few years of straight A's.

DR. RUSSELL: I am glad to hear that it was a valuable experience, although not necessarily academically. The academic rewards do not matter as much as the others.

QUESTION: There is one problem with your promotion of liberal education. Many disabled college students are supported by state vocational rehabilitation agencies, which are very clearly vocationally oriented. Students have to justify their education in those terms. Can we change those policies?

MR. REITWIESNER: I think too much emphasis is put on employability; we put a lot of funding into training students, with the ultimate goal of their getting jobs. But I think that, as Dr. Russell has said, there is a lot to be said for developing the whole person. You cannot expect a person to get a job if he is not developed physically, socially, emotionally—in every way. I wanted to ask Dr. Russell something relating to social development. You mentioned, for example, that you wrestled. You mentioned some personal distress that you had encountered in various experiences. Among the students I work with I have found that such sports as wrestling and swimming are not as socially acceptable as tennis and golf, and I was wondering how you overcame the problem.

DR. RUSSELL: I did not. I did not. But you see, wrestling was a very valuable thing for me. Not that I was especially good at it, but it brought me into combat–the basic archetypal human conflict, man against man. The other chap says, "I can see. You can't. Boy, you're a poor chap." And I say, "Am I? Come on, let's find out." And we get right down to the absolute basics. I have gained the respect of quite a few people that way. I worked at that because I liked it and it brought me into real and continual contact with people whom I might otherwise never have met; and they had to deal with me, they were forced to deal with me, as a person. They could not just back off the mat and say, "Well, dear, goodbye, it was nice to meet you." They had to face up to the fact that I was there. It is not a carryover sport like tennis or golf, but I still roll around on the mats with the wrestling team at Franklin and Marshall. I cannot compete with them, but that does not matter, I get a workout. I mentioned wrestling. But there is no particular virtue in wrestling. If you are good at checkers, try that, work at that. Anything. Playing the piano. I did not play the piano; if I had, that probably would have been immensely useful. Or the guitar. But that was before the "discovery" of the guitar. Solitude is the real pit. It invites suicide for the handicapped. How does one get out of that solitude? Wrestling is just symbolic of a way to begin coming forth socially. Any kind of skill or interest brings forth, whether it be checkers or dirty jokes. The focus does not matter. What matters is that it provides the opportunity and even creates a necessity for human contact, and that is what counts. The things that have brought me together with some of my very best friends were, in themselves, trivial things, such as a broken spark plug wire. But out of dealing with that, I made friends. And this is what happens--it creates contact. I do not care what the interest is. So long as you pursue it, you are going to find somebody else who also cares about it. We are marvelously unpredictable human creatures, and you will find somebody to share your interest, whatever it may be.

But you are going to have to do something. You cannot just sit and hope that they will come to you. It is an active pursuit. So, anything that creates a joint pursuit is valuable. That is why cocktail parties are, for the most part, just a waste, they are not a pursuit of anything. I have met people at cocktail parties that I thought were absolute blobs. But when I get them out in the garage or in a boat fishing–doing something together because we are both interested–then they come alive as people. You begin to move toward each other. That is when you begin to make contact for the most part. It is the active pursuit of an interest–whether it be wrestling or checkers or whatever–that is going to count as the most important thing for anybody, but particularly for the handicapped.

QUESTION: I went to a school for the deaf and I was trained to be a

commercial artist even though I had a high IQ, a high academic score, and so forth. I got married and had three children, but I was never happy being a commercial artist. So at a late stage in my life I had to change careers. Now I am an administrator at a school for the deaf and I am the happiest person in the world. I find that now I relate better to my family, too. And I am making three times the amount of money that I ever made as a commercial artist.

QUESTION: As someone who worked for a number of years with the Office of Vocational Rehabilitation (OVR) in New York State, I would like to say that the first year is generally regarded as an "experience year." Students do not necessarily have to be that successful academically to maintain their sponsorship. If they are not successful for two or three years, then there is a problem with the client's educational situation, anyway.

QUESTION: I wanted to major in philosophy, and OVR would not sponsor me. So for four years I borrowed money. The fifth year they agreed to sponsor me, but then they tried to place requirements on my program above and beyond what the college itself required.

MS. BEIDEL: Let me say a word on behalf of OVR. Had it not been for them, I would not have made it through college; I would not be here except for them. About the standards they have for grades: They forced me to study deep into the night. I had been educationally disadvantaged but I graduated with a grade point average of 3.85 because of the standards they set for me. Also, if they had not required me to pursue a vocational education, I would not have received the offer I did—as a recruiter/counselor for the handicapped at the New York City Board of Education. So it depends on how you deal with the setting of high standards. For me it has been a great source of enrichment in my life.

QUESTION: I have had some experiences with OVR too. I remember one time when I told a counselor everything about myself and he did not know what to say to me. At that moment, I saw that he was human like everyone else. Sometimes when you need something from somebody you have to work through with them the common factors you enjoy. Some counselors at OVR are more receptive than others.

QUESTION: Dr. Russell, would you say that the waitress you talked about was also likely to be racist?

DR. RUSSELL: There is a similarity, of course, between racial prejudice and prejudice against the handicapped; and I suspect that the laws have not wrought much change. The kind of thing that will bring change is the gradual making of friends. I have never believed in

separatistic solutions. In the 1960s there were very strong separatist movements among black students that taught, and I argued vigorously with them trying to explain that from my experience, separatism was badism. Separatism is what I have been trying to fight all my life and will continue to fight. I will never be able to complete the fight. There is always going to be that other waitress in the next diner, and you are going to meet her. That meeting is an opportunity. It is an infuriating one, I know; but if enough people go around, she is going to get used to us. We are just using the waitress as a symbol, right? She is no different from the college president.

MS. SCOTT: One of the goals that the Distinguished Lecturer Series planners had for the panel discussions was that everybody should pool their ideas and direct them toward particular issues; we wanted people to talk about some of the ways we can organize and bring about changes, such as having buildings made more accessible and having admissions training programs set up so that admissions officers will not discriminate. I was wondering if anyone on the panel would like to address themselves to the issue of what we can do about some of these problems?

MS. BEIDEL: The New York City Board of Education at 65 Court Street in Brooklyn will be servicing the handicapped population as soon as I get on the payroll. We would like you to start writing or visiting us. Our office came about as a result of affirmative action. I want you to know that this is just a beginning. We do not yet have all our resources and I would appreciate your sending us any relevant material.

QUESTION: I would recommend that if this lecture series is published it be sent to vocational rehabilitation offices all over the country—especially this session stressing the importance of extracurricular activities and liberal education, because OVR does not consider that a part of the academic function. As for being "indebted" to OVR, I think that is not right. OVR receives funds to educate disabled people. They are not doing us a favor. I think it is critical that they see that higher education is more than mere academics.

DR. HOURIHAN: I want to mention that right now, in Washington, Congress is working on amendments to the Rehabilitation Act of 1973. Every five years particular pieces of legislation are worked on, and the rehabilitation legislation is now being worked on in the Senate. If you want to be an instrument of change, whatever your viewpoint, write to your senator. And do it this week, because next month it will be acted upon. Congress will enact new legislation incorporating all the amendments. If you want to have input into the process, now is the time to do it. Disabled people can, if interested, provide input at this time and be instrumental in bringing about changes.

QUESTION: I am thoroughly delighted that the legislation is being worked on and that it does initiate certain changes relating to mainstreaming. But I want to mention another dimension, in addition to architectural change, that has to be worked on—and that is resistance. There are teachers who are resistant to having students who are disabled because they find it too uncomfortable to deal with their presence. I think that interpersonal relationships, which Dr. Russell spoke about today, are important for all of us; they must be worked on. We also must work on the resistances that students have in dealing with others who might be different in some way. We are missing a whole dimension that is necessary, and we can never legislate that. That has to be part of the guidelines that are sent to the schools along with architectural guidelines. We need to set up sensitivity workshops for teachers and students.

QUESTION: One man I know is attempting to organize committees for the handicapped in every community in New Jersey. We should actively inquire of the mayor and the local government in our communities, "Do you have an active plan to organize an office for the handicapped?" An effort such as this would contribute greatly to the organization of the handicapped people, while also helping to achieve their goals.

MR. KEMP: I would like to mention briefly that awareness training is included in Section 503—in the affirmative action section of Title V of the Rehabilitation Act of 1973. It stipulates that supervisors should be taken through an awareness training that will make them more familiar with the problems that handicapped persons face and with the functional capabilities of many handicapped people in a variety of limiting conditions. This is something that our company does, and it can be done by many people as long as it is done properly. An attempt should be made to show in a very positive way the problems faced by handicapped individuals. Awareness training is also included in PL 94-142, the Education of Handicapped Children Act. Second, the Rehabilitation Act was addressed by Dr. Hourihan, and it is quite true that Congress is trying to amend it, to expand it beyond a vocational rehabilitation concept with just employment as the ultimate goal of rehabilitation. They are trying to include the concept of independent living—which hopefully expands the capabilities and objectives of handicapped people—by providing much broader social, cultural, legal and financial services. I think this is very good and very positive. The big concern in Congress right now is that it is going to be very expensive. I do not know how the rehabilitation departments are ever going to be able to handle it. Rehabilitation counselors still are job-oriented because the legislation has been pushing them in that direction. If the amendments are put through, I think we are going to see a broad change—a better deal for handicapped individuals in general.

My third point is a commercial, because people from Mission, Kansas do not get to Cranford, New Jersey very often. I have about twenty-five copies of the *Section 504 Compliance Report*, which is a newsletter published by Kemp & Young, Inc., as well as other types of publications. You are welcome to look at them and see if there is anything of interest to you.

QUESTION: I personally believe that the way we disabled people will get our rights is not necessarily by asking the government for them but by organizing ourselves. I think we should take advantage of this meeting today to pursue that objective.

Margaret Chanin is Director of Oral Disease Control at Meharry Medical College. She is an active member of many organizations which serve the disabled in Nashville, Tennessee.

Education in Dentistry and the Health Professions

Margaret Chanin

Meharry Medical College

I am very appreciative of being asked to come and share with you in this program. However, I feel reluctant to talk about dentistry as a career goal, because entry into dental school, like entry into the other health professional schools, is very difficult at the present time.

When I embarked on a career in dentistry, I had not heard of the distinguished psychologist Abraham Maslow and his hierarchy of values. But I had discovered that a career in medical technology was not going to meet my need for economic security. At the conclusion of my medical technology training I had been invited to remain on the staff for the munificent salary of $90 a month. I realized I would have to look elsewhere if I expected to pay my college bills. Remember, this was near the close of the Great Depression. Economic security was an important consideration, and dentistry did offer good economic prospects.

Perhaps one of the strongest values, or needs, in selecting a career is that of personal fulfillment. For me, the sense of being needed was a value I became strongly aware of at a very early age; I was taking care of all the little babies on the farm, was nursing everything I could find that looked even halfway ill. I knew that whatever I did in life it would have to include being involved with people. Certainly, as a dentist one is—unless involved in full-time research—daily involved with people. One must educate patients to be responsible for their own oral health, and one must direct one or more auxiliaries in the office, in addition to carrying out the more skilled procedures oneself.

Two other values are mentioned by Maslow: our need for the recognition, approval, and respect of others; and our need to experience a sense of belonging. Certainly a dentist has every reason to feel proud of being part of an honorable profession, one that has a long history and serves a vital need in the community. This has been my experience over the years, living in many communities. And I have now been in Nashville for fifteen years. A dentist's services are in constant demand, provided the right location is selected. (I will say more about that in a moment.)

Like the other health sciences, dentistry is today in a state of ferment. To mention just a few of the trends and changes that are taking place: (1) Legislation before Congress to alter the traditional modes of health service delivery in this country, and the rise of consumerism, are affecting dentistry just as they are medicine. (2) The cost of malpractice insurance seems to be rising higher and higher each year. (3) Increasingly, dentists are concentrating on diagnostic work and the planning of treatment, with more of the routine procedures being delegated to auxiliary help, such as dental assistants, dental hygienists, and dental therapists. An experimental program of this type has been run by the government at the Manpower Center in Louisville, Kentucky, with dental trainees actually filling cavities. (4) The trend toward specialization is being challenged. (Probably 10% of all dentists in the United States are presently specialized in one of eight specialty areas.) Dental students are being taught to treat the whole person and to treat dental problems from a comprehensive standpoint. A wider range of skills is being developed than I was taught in dental school. For example, when I was in dental school, I knew that any patient I had who required root canal treatment would be referred to an endodontist. Thirty years later, I see our students routinely doing root canal work. I foresee a time when we will have more general dentists. (5) There is a growing trend toward group practice, with groups of dentists increasingly banding together to pool their skills and share the expenses of one location. I had never heard of group practice when I was in dental school. (6) In my day we were not taught community dentistry. We had only the vaguest notion of dental public health, and no courses existed such as the ones we offer students today to help them understand the needs of the community and regard the community as the patient. All of these concepts are just emerging; their full impact will not be known for many years.

If dentistry happens to be your vocational choice, then I would urge you to find out what it is that dentists do—talk to dentists, visit dental schools, visit dental laboratories. I find that some of our entering dental students have only a very vague idea of what a dentist's work consists of. Many are the first in their families to aspire to work above the blue-collar level. A colleague of mine claims that most of the people who go into dentistry are introverts—that they really do not much like being with people, and that they tend to need the feeling of security afforded by working in little rooms. Yet if one wishes to succeed as a dentist, one has to learn to be at least a compensated introvert; one has to learn to like people, or one will not be successful. The few extroverts who go through dental school eventually go on into public health or into politics. When I meet or read about a dentist serving in the legislature, I always think to myself, "Aha, there is one of those extroverts who couldn't stand working all day on the little tooth of a little person in a little room; he had to have a larger arena for his skills!"

Dental school catalogues do not say that applicants must have a college degree. They give the basic requirements as eight hours of inorganic chemistry, eight hours of physics, six hours of English, etc. However, I would advise you to obtain a college degree. The last survey I was able to find in the literature related to 1972; in that year 70% of dental students had bachelor's degrees. But when I entered dental school there were many in my class who did not have such a degree—I among them, to my regret. By the time I graduated from dental school I had lost my arms. I knew I would now have to train for something other than clinical dentistry—obviously I could not practice dentistry without hands. In reply to my application to the University of Michigan's school of public health I received a very polite letter that said, in effect, "Sorry, we cannot admit you to a graduate program without a bachelor's degree." I had been naive enough to think that my dental degree would be sufficient to get me in. So I had to go back to my undergraduate college and spend four quarters getting that bachelor's degree before I could again apply to the University of Michigan.

I am frequently asked the question, "Have you encountered any sort of discrimination because of your handicap?" I guess the answer would have to be yes, when I applied for admission to the University of Michigan's school of public health. But I was not aware of it at the time. Years later I was told that when my application was being discussed the dean had said, "I don't believe she could do the work; the difficulties would be insurmountable." But another member of the admissions board had spoken up: "I saw her once at a Dental Association annual meeting and was very impressed with how she functioned without arms." As a dental student I had served as a guide at the meeting and one afternoon had manned a clinic. I am sure that God planned for that man to serve on the admissions committee that day. Otherwise, the story of my life might have been quite different. I would not have been admitted to the University of Michigan; nor would I have met my husband and subsequently become the mother of two boys. I was taking my mother's advice: "Anytime you have an opportunity to do anything—do it! Do it whether you think you can or not." That was what I was doing at the dental meeting, acting as a guide and pretending I could man a clinic.

My mother would say, "No learning experience is ever wasted. You will always need it somewhere down the road. You may not know at the time where you will need it, but you will need it." Let me tell you the story she often told me. A young man, after studying architecture for several years, was called by God to become a minister and a missionary. Of course he had to transfer to another school and start all over again. He said, "Why did I waste all those years studying architecture? I am never going to need that knowledge." Some years later he was sent as a missionary to China. His first task there was to supervise the building of a hospital. Often it takes a long time before

one finds out why one spent time acquiring certain skills or knowledge. When I was tramping around cow barns and sewage disposal plants during a sanitation course at Michigan, I thought, "What is a dental health educator doing taking these courses?" Twenty-five years later, I went to Meharry Medical College as an administrative assistant in a program for the chronically ill and aged and the next year was invited to join the faculty. The first course I was asked to teach was community health. I opened the textbook and there was a chapter on sanitation –all those things I had learned years ago back in Michigan. So you see, one never knows why one is learning some things, and one is often quite irritated by the people who put a curriculum together. Sometimes it takes a long time to discover the relevance of certain things.

After one has met the prerequisites for dental school admission, one must take a dental aptitude test. It measures perceptual and motor abilities, reading comprehension, understanding of spatial relationships, verbal and quantitative skills, and knowledge of the biomedical sciences.

Several years ago the man who had just become the new dean of Meharry Dental School–a dentist, physician, and psychiatrist–greeted the freshman dental class during orientation week by saying, "Welcome to the most difficult curriculum you could have chosen." He explained that the students could expect to find dental school very different from their undergraduate days. At college they might quite often have found time to go to the library during the course of the day or to catch a movie in the evening. At dental school one is in class from eight in the morning until five in the afternoon, and evenings must be used for studying.

The first two years are spent studying the basic sciences–anatomy, bacteriology, biochemistry, etc. Clinical work is minimal, although we do try to expose the student to it in a few situations. The last two years are essentially clinical; an effort is made to build on the basic sciences in every way possible and to help students realize that the basic sciences are very necessary for successful clinical work.

I think that we at Meharry do more in behavioral science than some other dental schools. But dental schools in general have been trying to help students understand why patients react as they do–why they may be afraid of the dentist, why they may be "turned off" or made fearful by some of the things a dentist may say. In my department–Preventive Dentistry and Community Health–we have a psychiatrist who teaches entering students a basic psychology course. During the first two years she works in a class situation; in the clinical years she also makes use of videotape. She roams the clinic observing the students in action and tries to help them work better with people. In doing your predental work I would urge you to take all the psychology courses you can; they will help you to understand not only your patients but also yourself.

Now I would like to say a little about the cost of dental education.

Perhaps it is one of the more expensive of all types of medical training. At Meharry tuition alone costs $16,000 for the four-year course. This is exclusive of living expenses. Fortunately, there are scholarships and loans available. Most of our students do not come from wealthy backgrounds. Most of them have to work in the summertime. Meharry is an institution committed to the disadvantaged. That is our mission, as stated in our catalogue. Someone asked me recently whether it is considered a disgrace when one of our students fails and must stay longer than four years. I said, "My goodness, no. We just call them superseniors!" When someone fails a course and yet performs satisfactorily in the other courses, he or she is allowed to audit ahead and repeat the course when it is next offered. Then when the course has been passed, credit is granted not only for that course but for all the ones being audited ahead.

In a drive to produce more dentists, the government has been requiring dental schools to increase their enrollments each year in order to qualify for grants. I am convinced that the problem is not so much one of numbers as of distribution. Many areas in this country do not have adequate medical, dental, or nursing care. However, most young people are not attracted to the more remote geographical areas. They invariably choose to work in the cities, where there is already an abundant supply of health professionals. The New York metropolitan area, for example, has perhaps more dentists than any other area in the United States. Its ratio of dentists to population is three times that of Arkansas: New York, 80 dentists per 100,00 population; Arkansas, 27 per 100,000 population, the lowest in the nation. I see this discrepancy as the most urgent challenge facing the health field: how to entice, encourage, and challenge young people to go to the underserved areas. The government is trying out some incentive programs in designated areas, but the success of this approach is not yet known.

Dental hygiene is a two-year course that trains the student to do patient education and prophylaxis, or cleaning of the teeth. Dental hygienists are in short supply in many areas. There are only about 16 dental hygienists to every 100 dentists in the United States. Most of us who help to train dental hygienists feel that they are grossly overeducated for the work they are permitted to do, and many of the journals and articles that I have read seem to endorse this belief. In most cases hygienists are not given the opportunity to use the knowledge they have acquired in school.

Now I want to say something about how a handicapped person can function in an educational institution. I personally do not *feel* handicapped. I never have felt my handicap to be a great problem—other than that of adjusting to physical situations. I have found myself locked in the faculty bathroom and wondered if I was going to be there all night. Eventually I found the best solution was simply to go upstairs and use the bathroom the patients use, because it has a door

that swings open and does not need a key. I realized that I might someday get shut into my own clinic because of its round doorknob. I had to get a screw put into the side of the knob that I could catch my hook on. Now I am free to come and go as I wish. I have often said, "When I'm reincarnated there are going to be square doorknobs on every door!"

Sometimes the dental assistants call downstairs and say, "Dr. Chanin, could you please bring that tray upstairs for me?" Were I to drop such a tray, teeth would scatter in all directions. And I cannot carry everything in my pockets. I discovered that there is such a thing as a one-armed tray—a tray with an arm over it and a chain attached. Using my hook, I can carry whatever is needed up and down those steps, safely. I have since found scores of uses for that tray. I have one in the office, another at home. If I want to carry a pie or a cake to a neighbor, I put it on the tray and go marching down the street with it.

These are the kinds of little things that all of you already know about, because you yourselves make a hundred adjustments every day to cope with the physical inconveniences you encounter. As a handicapped person functioning in the professional world, these are mostly the sort of things that I have to overcome. And they no longer bother me. I have to be willing to write with my teeth in front of a whole table full of people at a treatment planning council. (Do you know, they usually do not pay any special attention to me.) And I have discovered it really amuses the children when I am in the clinic, happen to be without a dental assistant, and have to write the records. Youngsters who are out in the hallway see me writing and say, "Oh, Mama, look at the woman with no arms!" All of you will constantly have to deal with similar situations. I try to be reassuring. For example, when children in the grocery store notice me and say something, their mothers are usually embarrassed. I often say, "Be so thankful that they're bright enough to notice." I try my best to make people feel comfortable, because people are so often ill at ease around handicapped individuals. When they come to realize that you are a person, they can focus on the person and not the disability.

There is one thing a handicapped person should always try to keep in mind: If one is on the same salary scale as everybody else, one cannot expect too many exceptions to be made for one. For example, being handicapped does not excuse one from work on committees in an educational institution. I work on the fringe benefit committee for the faculty senate, on the awards committee, and on the library committee. Recently the chairman of a committee on which I was serving asked, "Dr. Chanin, would you compile a report on all the training sites that we could possibly use in Davidson County and give us the information at our meeting next week?" I really think that most handicapped individuals give their employers full measure for the dollars they are paid. I think most handicapped go the second mile. One goes to work many of the times that a person who is not handicapped would

stay home. When I was working as an administrative assistant on a program for the early detection of cancer I talked about oral cancer to just about every community group over age thirty-five in the city of Nashville. Even when it was raining I would have to walk the several blocks to and from my car carrying the flip charts needed for those excursions.

So much for the way I function in an educational institution. Meharry has been fair in promotions and fair in salary. I never have had to ask for a raise in salary or rank. We do have an unusual number of women faculty in our school. The chairperson of my department is a woman, and the former chairperson—also a woman—has just been made dean of the dental school. The department psychiatrist is a woman, the department clinical instructor is a woman, and the department educational specialist is a woman. Right now we are getting ready to hire a new department secretary, and the other day the dean said in jest, "I have written a job description for the position and it specifies that applicants should be male!"

My first experience working around handicapped people was during the war, when I visited hospitals. Later, I became absorbed in my home and in the community--raising my children, being active in my church and PTA. I did not get involved in handicapped groups at that time, because I found such association depressing. More recently I have come to realize that I cannot go through life just being concerned about myself. In 1970 I received the National Handicapped Professional Woman of the Year Award and then was asked to serve on Outlook Nashville, an organization devoted to the needs of handicapped children and young adults. My first impulse was to say, "No, I don't have time for it." Yet, I was finding time for the Cancer Society, for a home for the aged, and for various other activities. I told myself that it was time I grew up, that I should be able to involve myself with handicapped people without becoming emotionally upset and depressed. These seven years that I have been working with handicapped people have been rewarding. I have not found it depressing. On the contrary, it has been inspiring and encouraging. And I felt very honored when our governor selected me as one of Tennessee's sixteen delegates to the White House Conference for Handicapped Individuals. I do not know how much was accomplished there, but I feel that the conference did help to focus attention on the problems of the handicapped. During the conference one was reminded over and over that the problem is not a lack of laws on the books. It is a matter of their being enforced. I have met with various groups in Nashville to share the knowledge and insights gained in Washington.

Handicapped people have been given a new visability on television and in the movies. Ten years ago, would *The Other Side of the Mountain* have been made? I do not believe so. It is the most thrilling movie I have ever seen—the true story of Jill Kilmont, who was to have been an Olympic star. Then there was *A Little Inconvenience*, shown

on television at prime time last year, about a young movie star who had lost an arm and a leg and yet learned to ski. In Nashville some television newscasts are accompanied by captions and by sign language. If nothing else, the White House conference has focused attention, made the public aware.

The mayor of Nashville is very dedicated to trying to serve the handicapped. He has had a film made to demonstrate to government offices the environmental barriers that exist in the community. And in every one of our city government offices someone is required to know sign language.

I serve on the Mayor's Advisory Committee for the Handicapped, along with a number of other handicapped individuals. At our first meeting the mayor said, "I want to apologize to every one of you in this room. For twelve years I served as your congressman in Washington and I never noticed there were no curbcuts around the Capitol, around the White House, or around our capitol's other shrines and monuments. This makes them completely off-limits to people with walking disabilities. Not until we had our Tennessee White House Conference and I was informed that we must have curbcuts around our auditorium and downtown did I even become aware that such were needed. I assure you that when I went to Washington to attend President Carter's inauguration, I called Representative Sasser and told him to please get busy on trying to have architectural barriers removed from federal buildings."

Curbcuts are just one of the many ways of eliminating environmental barriers. We have failed to realize that at some time in our lives all of us will be handicapped to some degree.

PANEL DISCUSSION

Panelists: Yvette Aarons, Long Island University
Armand Bakalian, In Touch Networks, Inc.
Susan Beidel, St. John's University
Peter Brown, Medgar Evers College
Paula Westbrook, Ramapo College

MS. BEIDEL: I found Dr. Chanin's lecture very inspiring. It gives me new encouragement and new hope that there is no limit to what can be achieved, given the desire and the willingness to work toward our goals.

I was born on the other side of the world, where parents to not believe that their daughters, especially if handicapped, should receive much education. The war broke out when I was fourteen years old. Unfortunately I was separated from my family. During the time I was separated from them, I realized, although unable to walk too far, that there had to be more to life than just remaining in the little corner that had been allotted to me. During the three months of a harsh winter under severe bombardment, I reached out and uttered a very

childish but sincere prayer, "God, if you can use me some day, let me not die. Otherwise, take over this wretched life." Somehow that request was answered. I miraculously survived the war and was able to rejoin my family.

My parents still did not believe it was necessary for me to be educated. But I had a burning desire to learn, in spite of never having been sent to school. The only people who would help me at the time were American soldiers stationed in Korea. They taught me the English language. When I first started learning (which was in 1951), I knew only about eight words of English. These soliders taught me, tutoring me one after another until in the course of ten years they had helped me to attain sufficient confidence and ability to become a teacher in a U.S. army school, teaching the Korean language to the American children.

It was a this point, in 1961, that my first American teacher, a sergeant, invited me to visit him and his family in Alaska. I came with wonderful plans of working to earn the money that would enable me to continue my education. But on a visitor's visa, I found I was not eligible to work. Once again Americans came to my aid. The people of that community got together and somehow made it possible for me to attend college in the town where I was visiting. I cannot begin to tell you what a great, fine thing that was. I had had only four years of elementary school; going to college was like a dream come true. The professors tutored me; students helped me, trying to instill confidence in me; my sponsor and his wife helped me to become a new person; people in the community reached out to help me in innumerable ways.

I wonder if you realize, in this country, how generous you people are. I realize it because I am from a part of the world where it is not so easy to receive this kind of help.

I attended college in Alaska for only one year. Then I married and children came along, which temporarily put an end to my aspirations to be something or become somebody. When my children reached the ages of twelve and thirteen, these aspirations began to stir within me again. I started doing volunteer work at the hospital, thinking that I should wait until my children grew up and went on their way, then I would go back to school. But my supervisor, a social worker at the hospital, said, "I perceive that you really want to go back to school, and I perceive also that you are hesitating, that you are waiting for this to happen. It won't happen if you just keep on waiting, you have to go forward." He gave me the name of a professor at the College of Staten Island. When I first went to meet the professor, he interviewed me and asked me about my life. When he decided to accept me on the merits of my life experience, I said, "Do you really want to take me? I am forty years old. And I have so little to offer." The professor said, "Susan, you are the one we want, you are the right person because you have the motivation to go to school." With the help of this professor and many others like him I began the long journey of being a student again.

Believe me it was hard. I am sure you understand, if you have gone back to school after many years, how trying the first semester is. Many times I wondered, "Why am I back in school? Why am I going through all this?" But I persevered. Now I have finally graduated with a bachelor's degree in psychology and am enrolled in St. John's University, pursuing a career in rehabilitation counseling.

Many people have come to my aid besides college faculty and staff. The Office of Vocational Rehabilitation (OVR) extended their help. And I have just been informed that I have been given a position in the New York City Board of Education as recruiter/counselor for the handicapped. The position was created only recently, as a result of affirmative action. I am very happy to be able to tell you about this, knowing that many of you here were among those who went forward and fought for the cause of equal rights for the handicapped. Because of that effort the door is beginning to open–just beginning. But if we all get together, if we are united in our power, in our resources, we can expand the services and opportunities available to the handicapped. We have been repressed for so long. It is time for us to educate society so that we will be recognized as persons in our own right, as persons who have as much to contribute as all other people put together, and more. I have come to the conclusion that if we have the desire, the willingness to work–deep into the night if necessary–there is nothing to stop us from reaching our goal.

Many times we joke about it, this little parchment certificate that proves we have graduated. We often wonder if it really is the key that opens new doors, doors that were previously closed to us. Today, I am glad that I have gone forward, that I reached out and was helped to find the key to that door. Because today I see that all the effort I put in and all the help I received is beginning to bear fruit.

Now the position of recruiter/counselor has been created. But we do not yet have any program, any direction. We will have to formulate our program, plan our direction. If you have any materials–any handbooks, pamphlets, resources–that you could share with us, I would greatly appreciate it if you would send them to us at 65 Court Street, Room Lobby, Brooklyn, New York 11201.

MR. BROWN: I am going to tell you something of my own beginnings and my training as a deaf child in a hearing world. Because I feel that any discussion of disability and education is generally better understood when expressed in terms of personal experience.

It is not known how I came to be deaf. I had not developed any speech by the age of two, and my parents became suspicious about that. Once deafness was diagnosed, I was fitted with a hearing aid and my parents set about finding out how to train me. My mother, a student of literature, served as a teacher for the Volta Speech Association for the Deaf in Washington, D.C., publishers of the *Volta Review*. She began a correspondence course with the John Tracy Clinic in Los

Angeles, which aided her in teaching me to speak and to understand her and other adults. An important factor in giving my parents direction and feedback was the months we spent at the clinic's summer Institute for Family and Community Living when I was three. They had a five-year program for the study of children with hearing difficulties, the results of which are the subject of the book *Deaf Children in a Hearing World* by Miriam Foster Fiedler. The staff at the institute believed that deaf children, like any other children, need and can make good use of an environment in which they are encouraged to do, make, experiment, investigate. This aspect of our education was considered to be at least as important as the maximization of hearing and the improvement of speech.

My early development had relaxed my parents, who decided to enroll me in a school for hearing-impaired children at the age of five and finally in an elementary school with hearing students. Of course at that time, 1948-1949, things were quite different from what they are today. My parents were college graduates and teachers, and their basic concern was the development of the intellect and the achievement of communication and normal behavior in relation to other people. So I was well prepared in curriculum and vocabulary by the time I reached first grade. Since I knew the work and all the others were busy learning it, I was able to concentrate wholly on overcoming the social difficulties I experienced with my peers. The end result was that I was well equipped to compete academically in the hearing world. However, just as irritated oysters produced pearls of varying quality and substance, my academic record was one of uneven attainment. I performed very well in what was important to me and produced mediocre results in what was not.

What I am pointing to is this: The whole person is important. Every child needs security and the chance to compete on an equal basis with other children. Schools for the deaf were and still are largely, I think, academically below the level of those for the hearing. But if my children were deaf—they happen not to be—my wife and I would be concerned today, on the basis of our personal observation, with ensuring their happiness and security in a school for the deaf, which would provide them with the experience of feeling at ease among, and of growing and relating to children like themselves.

I want to emphasize the language and communication aspect of personal development. I am not a typical deaf person. For example, I have never learned sign language. Because of my heavy emphasis on speech training and on the skilled use of what little hearing I do have, and with my wife and my friends as my entrée, I have more than one foot in the hearing world. I have what seems to be only a very tentative foot in the deaf world. (My wife kids me that I belong in neither world!) But just as a foreigner needs to be able to relax in his or her own native language, a deaf person needs to be able to relax using whatever mode of communication comes most easily to him or her.

With language skills come social skills, hand in hand. But all disabled persons should be permitted periods of relaxation with their peers. There is no escaping the fact that peer socialization often provides a much-needed respite form socialization with the able-bodied. This is why it is important that the formal educational situation be predicated on the needs of the whole person. The person who feels secure and is able to socialize will work to optimize his or her communication skills, whatever that entails.

MS. AARONS: I am a student at Long Island University. I was born deaf and I grew up in schools for the deaf. To me, the Lexington School for the Deaf was not a great place because the learning process was slow. It took some time for many of the students to learn from the teacher by the oral method. So after graduating I decided to go to a college for hearing students. When I went there, in September of 1977, it was very hard for me, being my first experience in a regular school with normal students. There was one other student with impaired hearing, but he did not know sign language because he had gone to a regular school. The college did not have interpreters; they had notetakers, but the notes were not enough to study from. So I transferred to Long Island University.

Long Island University has a department of special education that works with deaf children going to a school for the deaf. But I believe it is better for a deaf child to go to a regular school and to work along with hearing children. Of course one has to have an interpreter, but it is more of a challenge. It is better to be challenged and to experience failure, than never to have made the effort. There should be something to struggle toward.

MS. WESTBROOK: I am presently a senior at Ramapo College, a four-year college located in northern New Jersey. It is a fairly new school, only about six years old. If I sound like a publicity agent for the school, it is because I am very happy about it.

I became disabled when I was about fourteen. I myself have never had any kind of special education, have never experienced segregation. But I recall always being aware that there were students in special education classes. These classes were usually down at the end of the hall, and I wondered what went on in them. I wish there were more mainstreaming in the schools. After all, when one goes on to college, there are no separate institutions or special classes for the disabled.

Another thing, I think that colleges should try to recruit more disabled people, not only in the high schools but among veterans. They should reach out to where disabled people are—in nursing homes, hospitals, rehabilitation centers. The thing about college is that it is not just an educational or book-learning experience. In college one learns a great deal about life in general. Dr. Chanin's lecture is an example of what I mean.

Now that I am graduating I feel quite nervous about what to do. A college as accessible as Ramapo is like a kind of security blanket. The campus is easy to get around in; it is not like the "real world." There should be a process that helps graduating disabled students get started—career counseling, job placement. I have been in touch with the career placement office. With the new regulations, such as Sections 504 and 503, a lot more job opportunities are opening up, which is good. After getting an education one wants to be able to do something with it. I know that a lot of employers come on campus in search of disabled people because of the new regulations. Some people see this as reverse discrimination, and maybe it is. But it is a way to get into a job and I plan to use it. Once one gets in, one can prove oneself—what one can do and what one cannot do. So I do not mind how I get in. Sometimes one's handicap can be an asset. It is not always a liability.

QUESTION: I would like to ask Dr. Chanin how many disabled students are in her dental program?

DR. CHANIN: I do not know the number. We do have a third-year student who is a graduate of Gallaudet College for the Deaf in Washington. She is functioning well, though it may take her an extra year to complete the program. In radiology, there are two handicapped employees. One is paralyzed on one side; the other is a blind transcriptionist.

QUESTION: Is there any kind of outreach or affirmative action regarding attracting disabled students to dentistry?

DR. CHANIN: Not that I know of. The main thrust at Meharry is to work with students who are disadvantaged because of their background. We have a predominantly black student body and many from foreign countries, too. But we also try to provide opportunities for the handicapped wherever possible. Last year, when we needed a record room director, the clinic director came to me and said, "Dr. Chanin, do you think we could use a handicapped person to be in charge of the record room?" I said, "Yes, the right person could handle it. Anyone who is able to handle the emotional aspects—phones ringing, people at every window, and so on—could do the job, even if in a wheelchair." So I think that people at Meharry are receptive to trying to make a place for the handicapped.

QUESTION: Dr. Chanin, would you care to comment upon a blind man taking up the teaching of dentistry? I have heard recently that there is such a case.

DR. CHANIN: I did read in a journal of a dentist in Ohio who lost his sight very suddenly. He woke up one morning and could not see, and

the loss has been permanent. He is doing a great job in the community in such leadership roles as working with Scouts. However, there is no dental school in his city. He feels that if he were living in a city that had a dental school, he might be able to teach.

Part Three

Civil Rights

Frank Bowe is the Director of the American Coalition of Citizens with Disabilities and the author of *Handicapping America.*

Handicapping America: Barriers to Disabled People

Frank Bowe

American Coalition of Citizens with Disabilities

I am very pleased to be here with you, very pleased that we can come together to talk about advocacy and civil rights for people who are disabled–something that for me is very important, very meaningful. I would like to share with each and every one of you why I feel that the human and civil rights of disabled people form an area in which we can and must all work together.

Perhaps the best way I can start is to tell you that as I go around the country talking with different groups, I am often asked about last year's demonstration. Many of the media people–the people in television, radio, and newspapers–remember me as one of those involved in that demonstration. Many other people around the country remember me in that way also. And they always ask me a question that for a long time I had difficulty answering. But that question has become for me a cornerstone question. It has become a question that helps me to identify for myself what I am doing with my life and why all that we are working for in civil rights is so important. Let me share with you what that question is, the answer that I eventually found to it.

The question is: Why did we do it? Why in April of 1977 did disabled people throughout the United States suddenly decide to demonstrate? So many people have said to me–they have taken me into a corner, they have put an arm around my shoulder, and they have said–"Frank, why did you do this? Disabled people don't *do* things like this!" Well, why was it? Was it that all of a sudden everything became too much? Was it that in 1977 the oppression and the injustices just became overwhelming? Was 1977 a really terrible year? Were things so bad that we just could not take it anymore? Why at that particular moment did we decide to demonstrate?

Do you remember what happened in 1977? Thousands of people from all over the United States came together and took over the buildings of HEW in ten cities throughout the country. And in San Francisco they stayed in the HEW building for twenty-five *days*. Do you remember what happened in San Francisco? HEW ordered the demonstrators to leave the building. But the demonstrators would not leave. So HEW

said, "Well, we are going to cut off your supplies of food." What happened? The Safeway stores said, "We'll supply food for the demonstrators." And the Black Panthers said, "We'll bring it in." And they did. For twenty-five days we had Black Panthers coming into the building with food from Safeway stores. For twenty-five days we had demonstrators sitting in the HEW building in San Francisco. This is something that disabled people had never before done in the history of the United States.

Why did it happen? For a long time I had great difficulty answering that question, because so many different factors and influences seem to have combined to make it happen. Then, sometime later in 1977, I happened to be reading a book about the black civil rights movement and I found the answer to that question. I want to share the answer with you because it has been enormously meaningful to me and I think it will be to you. I think it will help you to understand what I mean when I say, "We must come together to form an advocacy coalition–all of us in this room, all of us across the country who have knowledge and capability on and sensitivity to this issue–we must come together." The answer was provided by one of Martin Luther King's advisers at the time they were preparing for the March on Washington. Hundreds of thousands of people were planning to march on Washington in support of the civil rights legislation, then before Congress, which was to become the Civil Rights Act of 1964. This adviser said, "People think that revolutions begin with injustices. They don't. A revolution begins with hope." If you think about that, if you look back to the spring of 1977, then you will understand that the reason disabled people came together and demonstrated as they did in the spring of that year was because *they had hope*.

It is a tremendously tragic commentary upon the United States of America that it was only in 1977 that disabled people came to have enough hope to protest. It took two hundred years after this country was formed–*two hundred years*–for these people to begin to have hope. This is what had happened. A law had been passed in 1973, the Rehabilitation Act of 1973, and included in it was Section 504, which many people realized was going to become the cornerstone of the civil rights of disabled Americans. Section 504 was very brief; it was the last section in the act, and it was only forty-four words long. In 1977, four years after passage of that law, there was still nothing happening on it. And you know as well as I do that if a law is passed by the United States Congress and nothing happens on it, it is just a "motherhood and apple pie" kind of law, in which the Congress says that all is well and good, and they pour Cheerios for breakfast; that kind of law. It is not something that has any teeth or any impact. That is exactly what Section 504 was four years after enactment–just a motherhood and apple pie law. For four years we had fought behind the scenes to try to get the law implemented and enforced. And at the

beginning of 1977, for the first time, we had some reason to hope that the law was at last going to become effective.

First of all, when Jimmy Carter was campaigning, he made a number of excellent promises, and one of them was that if elected he would vigorously enforce Section 504. Then, during the the transition period of the Carter administration, four people representing the American Coalition of Citizens with Disabilities (ACCD) served on the transition team. These people were working with the President's top advisers, and we sensed that something was going to be done about 504, that it was at last going to become an important and instrumental piece of legislation that would affect the daily lives of all disabled Americans. Then Joseph Califano, secretary of HEW, said he was going to come out with a regulation on 504. HEW was going to be the first agency to come out with a 504 rule. So there was reason to hope.

Then, a few months into the new administration, we began to fear for that hope. Colleges and universities, schools, hospitals, welfare agencies, social security programs, and many other interests that would be affected by 504 were putting an enormous amount of pressure on HEW to delay its regulation or weaken it. Similar pressure was being exerted by the governors of the various states and by some of the legislators on Capitol Hill. We began to fear for that hope. We began to fear that 504 would be watered down, would not become what we had hoped it would be. We began to feel that once again, as had happened throughout history, we would be too weak, too fragmented; once again others in our society would have more strength, more power, more influence than we had.

But we kept alive the spark of hope that had been generated. Throughout the country, disabled people determined that hope was not going to be squashed, was not going to be allowed to evaporate. So, for the first time in history, a nationwide demonstration of disabled people took place. That was almost one year ago today.

I am telling you all this because it is enormously important that all of us understand that the hope for which we fought so hard last year was the hope for which we still must fight today. We still must fight to keep it alive. It is a hope that goes beyond Section 504. Beginning this summer, every agency in the United States government that gives federal financial assistance will be issuing regulations like the one HEW came out with last year. Twenty-seven different agencies will be required by law not to discriminate against disabled people. This will be tremendously important, because housing, transportation, and much else will then be covered by 504.

In the area of private employment we are now moving more and more rapidly on federal contractors, under Section 503 of the act. As long as we can hold together and can maintain our hope and our faith, we will continue, as we did last year, the needed monitoring and vigilance. We have reason to believe that we will at last be able to effect in this country a broad-based social change that will be

tremendous in its effect. That change is going to say that disabled people have abilities and that they should have the right to achieve the limits defined not by their disabilities but by their abilities.

Those of you who watched *Holocaust* this past week saw what happened in Germany when the prevailing perception was that disabled people were useless. In Nazi Germany, the first people to be gassed were disabled people. That was in a society where the perception was that disabled people were not able, worthwhile, or important. But our hope, the hope that began in this country in 1977, is for a perception of disabled people as people, who *are* able, who *are* important—a perception that goes beyond disabilities to abilities. We know that the disabilities are going to remain; my deafness will continue; blind people will remain blind. But what we are aiming for, what the hope is all about, and what Section 504 is at last beginning to do is to make people in this country see beyond that hearing aid, beyond that cane, beyond that guide dog, beyond those crutches or that wheelchair—to the *person*. This is something that most people cannot do. They see the disability and they stop. It is extremely difficult for many people to perceive that a disabled person can contribute to limits that are defined by his or her abilities, intelligence, or potential, rather than by his or her disability. But that is what we hope to do—get people to see beyond the disability.

We need to draw a clear distinction between the word "disability" and the word "handicapped." As I said, our disabilities are not going to disappear, but what we can work on are the handicaps. In this room today I am not handicapped. I can talk to anyone here and you can talk to me because I have an interpereter. I am still disabled; I am as deaf as I ever was—as I was this morning, as I will be when I go to bed tonight. But I am not handicapped in this room. And because this room is accessible, people, whatever their disability, can get into it. So the people in this room are not handicapped. They are still disabled, but they are not handicapped. This means that the people in this room can do whatever their intellect, their knowledge, their training, their ability enable them to do.

That is the hope, *that* is the ideal, *that* is the society we are striving for. *That* is what Section 504 marked the beginning of—a society where accessibility is a reality, where people can begin on an equal footing. Disabled or nondisabled, everyone can come in and begin on the same level, under the same kind of conditions, and go forward as far as they can take themselves, without unnecessary obstacles or barriers or handicaps.

But the hope that was born in 1977 is something we will have to fight to keep alive. I put great stress on this because day by day, as our movement gathers strength, more and more people become affected by and aware of what is happening. There is a resistance growing up. In the wake of every social movement, every civil rights movement in this country, a backlash, a resistance has developed. It will happen to

the disabled movement too. It will hapen because of costs. It will happen because of fear and ignorance. Perhaps the best way I can illustrate this is to tell you about a friend of mine who was disabled in Vietnam. He is a lawyer, and he and I were working together to get the transbus, the bus that is accessible to everybody. We were working to get that bus, but we found ourselves up against a group of operators and owners of the buses called the American Public Transit Association (APTA). The APTA was fighting the transbus. They kept giving their objections and we kept countering those objections. They said, "It is not technologically feasible." We pointed to the research studies; we brought in engineers who proved that it is feasible to build a bus of that kind. They went on to their second objection and their third and their fourth and their fifth. And what it came down to was this, in the words of my friend from Vietnam, "In the final analysis, the opposition of these people is based on the simple fact that when the bus comes down to the stop, people like me are going to get on. And they do not want that."

There is opposition in this country to disabled people being mainstreamed into society. There is fear, there is igonorance. We have got to face up to that. We have got to realize that there is this kind of opposition. It is not just a question of cost; it is a question of uncomfortable feelings, of fear. We have to recognize that that fear is real, and it is something we are going to have to fight against. We are going to have to keep our newborn hope alive in the face of this kind of ignorance and fear. We are going to have to keep it alive in the face of people who say it will cost too much to make this country accessible to disabled people. We are going to have to keep it alive in the face of whatever obstacle is thrown in our paths. And when I say "we" I mean all of us here today, whether disabled or able-bodied. Because the men and women who were invited to this conference are people who have some knowledge and understanding of disability, some sensitivity—much more so than the average American. Many of you are special educators or students in special education, people who are working or learning in the area of disability or in a discipline that includes work with the disabled. As such, you are unusually well qualified, unusually sensitive and knowledgeable. If you do not join together with us to form a coalition that will forge a change in this society, who will? If you do not fight with us, who will? If you do not understand, and accept, and advocate for accessibility in housing and transportation and social programs, who will? So I say to you that we must work together. We must join hands together. We must reach out a hand, one to another, and grasp the hands of one another. We must work together to rehabilitate America. We must work together to overcome the barriers that face disabled people. We must work together to achieve what the Supreme Court once called "independence and self-confidence; the feeling of creativity; lives of high spirits, rather than hushed, suffocating silence." And we must work together now. For if

we do not, we will, with Langston Hughes, "See what happens to a raisin in the sun, and a dream deferred too long."

PANEL DISCUSSION

Panelists: Adrienne Asch, Columbia University Teachers College
Helga Bendix, Westchester Coordinating Committee of the Handicapped

Moderator: Thelma Schmonies, HEW Rehabilitation Service Administration

Contributor: Kipp Watson, Disabled In Action

MS. SCHMONIES: I am very glad to have the opportunity to share with you some of the activities of the regional office.

First, by way of some background: Region II Office of Rehabilitation Services of HEW covers the states of New York and New Jersey, as well as Puerto Rico and the Virgin Islands, and it is our responsibility to administer the Rehabilitation Act. The act carries with it a section called Title V, which in turn carries within it Sections 501, 502, 503, and 504. To fill in the Title V picture, let me say that Section 501 refers to opportunities for employment in the federal government, and it is the responsibility of the U.S. Civil Service Commission to see that qualified handicapped individuals are given the opportunity for such employment. Similarly, Sections 503 and 504 provide for employment privileges as well as services in the private sector. Section 502 mandates the Architectural and Transportation Barriers Compliance Board, which covers, I believe, nine domestic agencies. All agencies that provide federal funds for building or transportation programs have to comply with nondiscrimination. The reason I am mentioning all of these things is to emphasize again, as Dr. Bowe has done, the very broad implications of Title V, and that we have only just begun to see these implications.

While Section 501 is administered by the U.S. Civil Service Commission and 502 by the compliance board, Section 503 is under the jurisdiction of the Department of Labor's Employment and Standards Division and Section 504 under that of the Office of Civil Rights. You will notice that none of the sections is administered by the Rehabilitation Services Administration (RSA). However, it is our feeling that Congress, by putting this section into the Rehabilitation Act, recognized that RSA was the focal point for services to the disabled in this country and intended that it should be. So we have without benefit of portfolio, assumed responsibility for the role of public educator. We have utilized some of our limited training funds to award grants around the country to develop training materials. Some of you may have seen these materials; I will be happy to tell you what they are if you are interested. We have, wherever possible,

met with contractors, grantees, and organizations to indicate the procedures and provide the technical information that those who are not accustomed to working with handicapped people need. And we have met with individuals seeking information as to their rights. I do want you to know that this advocacy within and outside the government is being conducted wherever possible by RSA. As a certified rehabilitation counselor, I would be pleased if students in rehabilitation counseling programs would also be invited to such activities as this in the future. It would, I think, be meaningful both to you and to the students in those programs to have them participate in your deliberations.

MR. WATSON: I think Frank Bowe has described very eloquently, very movingly, why we have to destroy handicapism--because handicapism destroys people. Yes, disabled people were the first to be cremated, the first to be experimented on, the first to be sterilized. A couple of weeks ago, the Supreme Court ruled that a judge who had ordered the sterilization of a fifteen-year-old girl because her mother described her as "somewhat retarded" should be given immunity in a civil suit. The argument was that the judge had acted within his authority. But the judge had never asked the girl, "Do you mind being sterilized?" He had just assumed that the grounds for sterilization were adequate. Later, when this girl married, she experienced the horror of what society inflicts when it does not provide due process.

Why are disabled people institutionalized? Why, until just a couple of years ago, was it permitted for disabled people to be educated in segregated school systems? Why have disabled people so long been denied access to the social arenas of life--theaters, movies, sports stadiums?

Biological theories have prevailed in society's values and mores for hundreds of years. Darwin expounded the theory of natural selection, a theory that justifies the destruction of those who are perceived to be inferior. But we live in a land where our Constitution demands equal opportunity. The Fourteenth Amendment says that no person shall be deprived of life, liberty or property without due process of law. We have an obligation to our founding fathers to see that law becomes a reality. Where do we go from here?

In Disabled In Action we have some ideas. We feel that there should be an amendment to the 1964 Civil Rights Act and through the same enforcement mechanisms, extend the protection provided by that law specifically to disabled people. We have to work with other groups that are also fighting the evils of discrimination, the groups fighting racism, the groups fighting sexism. Last week 20,000 people were in Washington, D.C. They were there to bring a message to the Supreme Court--that affirmative action is a legitimate mechanism to end the self-perpetuating cycle of racism. My hope is that people here will join with such active civil rights groups as Disabled In Action. There are several members of Disabled In Action present, and they will be very happy to speak with you about our organization--describe our meetings

and what we are trying to do. I hope you will approach them and find out how you can help in coalition building.

MS. ASCH: In their presentations, Frank Bowe echoed the words of Langston Hughes and of Martin Luther King, and Kipp Watson spoke about a development of Disabled In Action that I, even though I am involved in the group, did not know about—that Disabled In Action had supported the progressive forces in the Bakke affirmative action issue. I think both of them were making clear that people with disabilities have to stand together not only within their own disability groups and not only as people who are disabled but as people who have something very important in common with other groups in this society—members of ethnic, racial, and religious minorities, and women. Taken all together, that adds up to a lot of people. Even though we have all made some progress by ourselves, if we could stand together as a unified force, we could get a lot more done.

My saying this results from a personal and political evolution that I would like to tell you a little about. In 1969 I graduated from college and came to New York to seek my fortune. The employment situation was not very bad in 1969, and all of my friends who did not go on to graduate school (not many in those days) proceeded to get jobs—perfectly reasonable, interesting-sounding jobs. So I applied for them too. I applied for about seventy of them, and I finally got one. I got a dictaphone typing job in a typing pool. But more to the point than the job I got were some of the jobs I did not get. After not getting one job for which it was quite clear I was particularly well qualified by reason of my training and experience, I called up some federal government agency—maybe it was the Equal Employment Opportunity Commission—and found out to my absolute horror that although blacks and women were protected against discrimination there was no federal law to protect me. People could discriminate all they wanted against blind people. I called up a New York State office and found there was no New York State law to protect me either. So I filed a complaint with the New York City Commission on Human Rights; it was a very lonely business.

I am mentioning this episode because if it and many more like it had not happened, I would not have reincorporated my disability into my sense of identity. How did I view myself? I was a reasonably well-educated young woman. I was white and middle class; I thought I was entitled to whatever other people in this society were entitled to. Now, one should not have to be white and middle class to be entitled to that, but in any event I expected to get what I deserved, what my abilities merited. When I discovered that I not only was going to have trouble but did not have any legal remedies, I began to realize that some fighting had to be done—not just for the civil rights of other people, but for the civil rights of *my* people. That was a hard discovery for me. I do not know about the other disabled people in this room, but I

suspect it may have been a hard discovery for you as well. This discovery, whenever it has occurred in individual lives, has led me and many other people to do the kinds of things that Frank Bowe and Kipp Watson talked about—band together, form civil rights movements and political action groups, demonstrate, lobby, analyze statutes, fight for the passage of laws, and work to have those laws implemented once they are passed.

I am very proud to have spent three years at the New York State Division of Human Rights. New York State's antidiscrimination law as originally passed protected racial minorities, religious minorities, women, ex-offenders, older adults, and younger adults. Since 1974 it has been amended to include people with disabilities, and I am very lucky to have been involved in helping to implement that law. There are pitfalls in the way any law gets implemented. And there are pitfalls in having people who know very little about the disabled start implementing a law that protects the disabled. Most of the staff of the New York State Division of Human Rights were nondisabled and had no particular reason to know anything about people with disabilities. Their experience was in dealing with blacks and women. They tended to regard disabled people as incompetent or limited or freaky or strange or frightening—just as all the employers did. But I think it is fair to say that they have been working and learning. And they have had a lot of opportunity to learn, because about 800 to 1,000 complaints have been filed by disabled people in the state of New York in the last four years or so. But we need more of those complaints. And we need more federal complaints. We need more 501, 503, and 504 complaints. However, to file such complaints, people must first believe that they really do have rights, and that belief entails a complicated set of emotional and psychological as well as legal processes. It means we have to believe in ourselves as people, in ourselves as people with disabilities, in ourselves as people who are competent and entitled to aspire to whatever people without disabilities aspire to.

There are two things that I hope I can get across. It is important for people who are disabled, and for people who are working with the disabled, to come to believe that we as individuals have rights and then to fight for these rights wherever they are infringed upon—whether it is in employment or transportation or education or housing or services. Fighting for our rights can be done as individuals, but it is best done collectively. So, I want to urge that people consider at least finding out about, if not actually joining, organizations of the disabled, that they begin working for civil rights. And let us continue thinking about coalition with other groups in this society to work for the enforcement of the rights of all of us without regard to the particular category we happen to be members of. I would like us to think about what we have in common and what we can all gain by working together.

MS. BENDIX: I would like to speak about the two aspects of this

whole topic that I feel I know best—the implications of being the parent of a handicapped child and the implications of the new education law. One of the first things I did when I looked at the program today was to amend the subtitle of this session to read, "Barriers to the *Parents* of Disabled People." I have a ten-year-old mentally retarded daughter, a Downes syndrome child with severe cardiac complications. However, my various activities, including sitting as a parent member on the Committee on the Handicapped in my school district, have put me in contact with people having all sorts of disabilities, and I really feel a great deal in common with the handicapped—in the broadest sense of that term.

As the parent of a disabled child, one is subjected to all sorts of barriers, both conscious and unconscious. The parents of any child have a great responsibility; when that child is handicapped the responsibility seems even greater, the load surely heavier.

Most of us have had no training to be parents and certainly no training to be parents of a handicapped child. How much we know about filling that role depends upon what our life experiences have been up to that point in time. Of course we go through shock; how we resolve that varies from individual to individual. We do our best to cope with the daily routines and with potential medical emergencies.

We are dependent upon professional input. Many of us have been reared in the tradition of relying on a professional, forgetting that while he or she may be trained in a particular area, other aspects of the professional personality reflect attitudes in our society that may or may not be to our advantage. The professionals, furthermore, do not always agree among themselves on the kinds of treatment or services that are needed for our child. Through all of the conflicting advice, to that extent are we then capable of making a choice? We also, depending upon the handicapping condition and on the advice we get from the professionals, have to ponder certain questions. In our decisions for or against surgery, in our decisions for or against particular kinds of services, we face questions that relate to the quality of life itself. Some of these are questions that parents suddenly have to face overnight; others they may have a couple of years to ponder. Remember, husband and wife, mother and father, are reacting as individuals; their background and training may bring them to different conclusions, so that we have potential problems within the marriage. And of course grandparents, relatives, neighbors—all want to have a say in the matter; and these voices may agree or they may conflict.

The parents, over time, have to be concerned about money. What are the financial implications? What kinds of services are available? Which particular doctors, services, should we commit ourselves to? Can we afford them? Can we get transportation to them? What are the implications for family life in terms of our other children? And there are other kinds of decisions. For example, I would like to go back to work. Can I afford to go ahead and do that? How does one cope with

all these decisions? Access to needed information may be easy, may be hard, depending upon whom one happens to encounter.

Dr. Bowe did not mention PL 94-142, the "right to education" law by name, but it is tied in with Section 504. In a sense this law is, for handicapped children and their parents, equivalent to a piece of civil rights legislation. It means that the handicapped child is entitled to a free, appropriate education at no cost to the parents. It mandates that the education should take place in the least restrictive environment possible, that children should receive special education and related services, and that these should be developed through an individualized education plan. And the law provides for due process. These are great steps forward in helping to provide the education and training that in later years, if all the other barriers we have spoken about today—architectural, transportation, employment—are removed, will enable our children to go out and hold meaningful jobs. But it is our responsibility today as parents to see that these services are provided.

However, parents are people, and there are great variations among them. In dealing with other parents as a member of the Committee of the Handicapped, I have seen that some parents can only just barely make it through the day, with the daily obligations and what have you. They are not in a position to stand up here shoulder to shoulder with us as advocates, much as they might want to. How they feel about the services they are getting ranges from gratitude to anger; they may be reluctant advocates or they may be very eager, activist types of individuals. Occasionally, some individual becomes somewhat overzealous, as I see it, and really gung-ho for a particular handicap. This as we all know, is something that inevitably produces friction and makes it hard to form workable coalitions. What we all have in common is really far more important.

With regard to implementation of the education law: I am active in my school district, dealing with all those other parents who do not have handicapped children. I have been assigned the task of going out and helping create support for the budget. Because at this point in time, much of the rise in school budgets is attributed to special education, I have been urged by the superintendent to take on this task. I know that not all parents can do it; it is one of the types of special obligations that I must assume. But as I pointed out to the PTA, I am only one among many; if I am quick with my words, yes, I can mention something about special education at a particular meeting. But I have to say it pretty fast, because there are all sorts of other organizational matters that others want to talk about and that are equally important. So, as a parent of a handicapped child working for advocacy, working for the best for our children, I find that one of the hardest tasks is working with the nonhandicapped in trying to get better education for our children.

MS. MILLER: I am a social work major, so one day soon I will be a

social worker. Very important to me is that role of advocacy, which seems to come my way every once in a while

I would like to share with you a personal experience. I came from the City University of New York, where my program was very good and my experiences with the handicapped students were very good. At Adelphi I found myself on a campus where the handicapped were not very well represented, and it was difficult for me. Everywhere I turned I seemed to have difficulty. I was told, "Mary, it's your job; you've got to do it." So Mary had to do it. She sat down with administrators and various other people, and she did it. Now we have a pretty good committee going. What I was able to accomplish was the organization of the handicapped students, the forming of a group.

But one thing that has emerged from this group is the discovery that many of us do not like being "grouped." Let me tell you about one of my own experiences. I was going into one of the buildings on the campus. There was a turnstile at the entrance, and I had just had surgery in the summer and was on crutches, so of course I could not make it through the turnstile. I said to the man, "Could you let me through?" and he let me through a special door. Then once I was inside the building I needed the elevator, and again I said, "Can you tell me where the elevator is?" and he said "Sure." He took me through behind the desk and as he was opening the door, a woman stood there and she said, "We let them use that door over there." And something inside of me turned. I did not know exactly what was the matter. I thought about it for a day, and when I finally came to a conclusion, it was that I did not like being called a "them." I did not like being grouped. We on the committee have discussed this problem and now are really trying for a different type of outcome.

Now, I have a question for Frank Bowe: As a social work major, and a handicapped person, the field placements I tend to get are therapy and nice quiet little things. And that is not what I do best. Let me tell you another little story: At the end of my junior placement I was working in a nursing home and we had a party. We played twenty questions: on everyone's back was put a name—the name of a very famous person—and we were each allowed twenty questions to guess what that name was. Knowing what they all thought about me, I guessed my name after about the third question—it was Ralph Nader! So I have quite a name to live up to. If you help me in any way, I would be gald to have any information you can give me.

MS. MURRAY: I have no training, so to speak, in being disabled. I am a registered nurse and have worked for a long time as a psychiatric nurse. Eleven months ago I was in a very bad accident and I was told I would never walk again, let alone work. I was discharged from a university hospital—the hospital in which I had been a nurse—with absolutely no physical therapy. I was just told that I was disabled and that I had to accept it. I did accept it. I accepted it for five months,

until my parents could not accept it any longer and told me it was time to get out of bed.

After a lot of hard work, a lot of looking back, I really can say I have seen both sides. I have gone from being a perfectly normal human being—working, functioning, graduating from a university—to becoming almost nothing, returning to a childlike state where everything had to be done for me. I am lucky, I really am. Today I realize that I can walk. Everything is basically fine with me.

I have learned a lot from your program. I have listened carefully to all you have said. I have learned about Disabled In Action; I have learned about Frank Bowe's group. This is the first I ever heard of them.

I really think it is time that nurses and doctors got educated regarding the disabled. I know now, that I, as a nurse, had a lot to learn; I used to assume that patients who had a handicap were not normal, that there was something else wrong with them. I know that sounds terrible, but it is true. Most nurses and doctors tend to do that. If you are in a wheelchair, we automatically think that your mental capacity is not that of a normal person. But you are more normal than any of us, really.

There is not very much that people can say when they see a disabled person; they stare, they do not know how to handle it. I was in a wheelchair for a while. When I first started to walk again, I started with a walker. I went back to work as a supervisor. I said I would try it for one week. It is ironic to see patients turn around and stare at the nurse coming down the corridor with a walker; it is even worse to see your own co-workers do that. People would go out of their way to be nice; they would tell me to get off my feet, to sit down. It was a new world for me, it really was.

I think that a lot of the time (and I say this only after much thought) disabled people have allowed this world to be created. You have allowed that image to endure. The image endures at universities; it endures with nurses, with doctors, with social workers. Now that I have learned about your groups, I am very impressed. Before, I was very skeptical. I thought I was coming to a session today where everybody would tell his or her story, and it would be one heartbreaking "Can you top this?" after another. It has turned out to be quite different and very informative.

But I think it is up to us to work for changes. For my part, I have decided that I will not let a single student out of the Molloy nursing program without letting him or her know that you do not treat disabled patients as though there were something mentally wrong with them. I think my whole life has been turned around by what has happend to me. But I am only one person. The counseling and placement staff of Molloy College are only a few people. I think that if you want to be unified, you have to let all of us know more about you.

QUESTION: There are some employers who, to comply with the law,

are hiring handicapped people just as token staff members and not really in recognition of their abilities. Agencies working with the handicapped are the worst offenders of all. Does anybody want to react to that?

MR. WATSON: I think you have raised a point that reflects pretty much what a lot of disabled people tend to feel—that they have to prove themselves. Yet study after study has shown that disabled workers, provided they are working in the area of their ability, are just as able as anyone else with the same skills.

Hiring one or two people who are disabled, or a very small number of people who are disabled, is a very common way for employers to get around their requirements under the law. Tokenism or underemployment or not hiring people at their true level are some of the many different ways that employers get around their legal responsibilities. And we have to address that in an organized way.

MS. ASCH: Let me make a couple of responses. I think that there are two issues embedded in what you are saying. One is that agencies (public and private) serving disabled people, and programs serving disabled people, have now realized—a realization that is long overdue—that in their own employment policies they should at least comply with the laws they are trying to get other people to comply with. So, they realize their responsibility to hire disabled staff members. There is no question that the agencies serving the disabled do not have the best record on employing the disabled. There is also no question that there are people being hired as tokens and there are people being underemployed. There are several ways to fight that. The first way to fight it is as members of advocate groups, dealing with the agencies as a unified body. The other way is for those particular individuals who feel they are being underutilized or improperly utilized to file their own complaints. In New York State you can file under the New York State Human Rights Law or you can file under the federal laws. Section 504 covers rehabilitation agencies as much as it covers anybody else. That is one point. The other point, relating to tokenism and proving oneself, is that the place to prove oneself is on a job. Disabled people should make a start, gain entry as it were and then prove themselves on the job and be accepted. Then they can, after they have proven themselves, fight for more rights.

MS. SCHMONIES: I would like to add a thought here. I appreciate your feelings about this matter. The law, at least as it is now written, says "qualified handicapped people." Unlike the other civil rights legislation, it does not have either quotas or timetables. And one of the problems that we have met in dealing with employers is that they find it very difficult to understand the complexities of the disabled—that we are talking about one individual at a time for one job at a time, and that

the accessibility or reasonable accommodations (and I am using government language now) that are appropriate for one individual are not necessarily going to be appropriate for all time for all handicapped people. It is this need to individualize and to be concerned with individual capacity that is very difficult. I am not offering any excuse. All I am saying is that it is difficult. There is a need for coordinated action; but there is also a need for individual action. Adrienne Asch sat on a planning committee in which we, at least in this region, brought together all of our RSA grantees, the university educators, and those in charge of rehabilitation facilities—not only to share with them what their responsibilities are under the law but to seek their cooperation with us. As I mentioned earlier, RSA has no direct responsibility under the act; but we asked these people to join us and to serve as role models and as technical experts for the people in their communities who do not know how to cope with the handicapped. We asked them to participate with the disabled in this effort in every way they possibly could. What Adrienne has said and what you have said are quite true. I am not suggesting that we have accomplished our goals either. Certainly there is this recognition by RSA of their responsibility as providers of services for disabled people.

I would like to share one other thought that has occurred to some of us. In the big metropolitan areas, such as New York, there are unfortunately so many people who need services that, in a sense, separate agencies are justified. But it seems to me that in upstate and rural communities, separate agencies for each disability group are not a viable form of service and not in the real spirit of Section 504. Because no matter how much each agency is concerned about its particular disability group, they will need to provide services and to hire qualified handicapped people in all disability groups. That is going to be another very difficult problem and we are going to have to work together on it.

QUESTION: If you become disabled after being hired or identify yourself as disabled after being hired, is that a reason for not keeping you on the job?

MS. SCHMONIES: That is the whole point of the Act—that if you are otherwise qualified the employer cannot deny you the job because you are disabled. That is what the law says.

QUESTION: I have just begun researching the "ripoffs" regarding appliances for the disabled, such as wheelchairs, braces, and so on. I wonder if any federal or state agencies are dealing with this problem.

DR. BOWE: I would like to say that the American Coalition is very deeply concerned about the cost and lack of quality of such products, and the problems that many people are having with them. We refer the

majority of people with complaints to the Federal Trade Commission, with the express concern of helping people to recognize and fight against discrimination and unfair trade practices. Unfortunately, we do not have the staff for handling complaints of that nature, but we can refer them to the appropriate authorities.

MR. WATSON: New York City's Department of Consumer Affairs has taken the lead in the country in the area of consumer advocacy for the disabled. The department is directly involved in monitoring the quality and cost of the products that are used by disabled people. I wonder how many people in this room know that a hearing aid costs as much to buy as a color television set, but to make it does not cost any more than a transistor radio. The cost of wheelchairs in the United States is two or three times as high as in, say, Great Britain, for the same quality. A suit has been filed against Everest and Jennings. And ACCD is involved in a monopoly suit—I believe that is in criminal court. The Department of Consumer Affairs has a very good booklet about the disabled consumer. Write to them and they will be happy to send it to you.

DR. BOWE: The Department of Justice in the previous administration began a case against Everest and Jennings for monopolization and unfair trade practices, and then dropped it. We were able to put pressure on the Carter administration to get them to reinstitute the case, and they did. They have a good case. We at ACCD are also suing Everest and Jennings. We are suing for damages on behalf of the disabled people who have had to pay too much for their chairs or who have not been able to get their chairs repaired properly. The Justice Department is working on a settlement out of court. I do not have all the details on that yet. Whether we proceed with our action will depend on the nature of that settlement. We would like the disabled people who have had to pay too much or have not been able to get their chairs repaired to be compensated. Anyone who wants information on the case should contact any ACCD office.

MS. SCHMONIES: Let me suggest that there is another kind of ripoff going on, which is also quite distressing. This one relates to the removal of architectural barriers. Unfortunately a number of people are taking advantage by charging exorbitant sums to make buildings accessible. When we found that people were making these "unusual" estimates, we in RSA met with our colleagues in the Department of Labor, the Occupational Safety and Health Administration, and CETA (Comprehensive Employment and Training Act) and with federal engineers. In this region, and hopefully the plan will be replicated throughout the country, the Department of Labor has sent out a program issuance to all the CETA prime sponsors urging them (1) to train and hire people to survey buildings and give some general cost estimates and (2) to train

CETA employees to make minor renovations. Thus two federal agencies can together provide a community service at no cost. This strategy will avoid a lot of unnecessary expenditures for the removal of architectural barriers. Outside of the installation of elevators, many of the renovations that need to be made are quite simple. There is an urgent need for people to be aware that hundreds and thousands of dollars do not have to be spent in every instance.

QUESTION: I would like to address my question to the young woman who talked about nursing for the handicapped. I am what you might call a very mildly handicapped person. I wanted to go back to medical school after coming back from Europe but I could not get into any school for medicine or nursing or medical technology. But I feel that the handciapped would make good workers in that area.

MS. MURRAY: There is a lot to be said for that. But in the field of nursing, anyone who is handicapped is extremely limited. That is not due to any prejudice. It is sometimes a matter of life and death. For example, in a case of cardiac arrest, it is of the utmost necessity that you be able to run—run down the hall to give assistance.

QUESTION: I am referring to the fact that there are borderline handicaps, where people can run and do have all the necessary capabilities. There are, after all, M.D.'s with all kinds of disabilities.

MS. MURRAY: I know that the school I am involved with at this point would consider applicants with disabilities. But once again, handicapped or not handicapped, you have to prove yourself to a certain degree.

MS. ASCH: I think the interaction that has just taken place is very important. Ms. Murray is a person who has lived in both worlds. As someone long involved with nursing and the medical profession she is expressing a view that says, "I understand that it is important for handicapped persons to be given the opportunity. But there are fields of nursing that judging from my personal experience, it would seem unlikely a disabled person could enter." I think the important point for us—whether as disabled applicants or a workers with the disabled—is to be very clear about what the law, state or federal, says. And it is important that assumptions not be made—either about a group or about a particular job. Each disabled person has to be considered for each particular job on the basis of his or her particular merit, particular training, and particular coping ability.

QUESTION: There was a fellow who was born deaf, and he went to a school for the deaf. Then he went to high school, but because of his deafness he could not enter regular college. He got married, had

three children. Then he began to feel that he was capable of going to college, and he went to school at night. When he finished college he decided to apply to medical school. He passed all the exams, but no school would accept him when they found out he was deaf. They told him, "If you can prove that you are capable of listening to the heart, we will accept you." He did not stop there. For about three years he worked with various engineers to develop a special stethoscope, and when it was developed, it was more sensitive than a regular stethoscope. He demonstrated it to the medical school and they accepted him. Now he works in San Francisco, at Babies Hospital, and he specializes in working with children who are deaf.

MS. SCHMONIES: The Supreme Court ruled just a few weeks ago that a college could not refuse to accept an applicant just because he or she was deaf.

MS. BENDIX: My comment is again from the parent's perspective. We parents are very appreciateive of everything that the adult disabled are doing in terms of getting legislation on the books that will help us in our job of raising a disabled child. I find, however, that the adults—and here I mean the disabled and the nondisabled—have a tradition of turning their backs on families. I find little communication between parents' groups and adult disabled groups. I wish there was much more communication, first of all because you can help us; but also because we need your help—we still have a long, hard road to travel.

Curtis Brewer, Esquire is the founder of Untapped Resources, Inc., a law office which addresses itself exclusively to the legal problems of the physically handicapped.

Civil Rights Aspects of Disability

Curtis Brewer

Untapped Resources, Inc.

To address the subject of civil rights aspects of disability seems to me to be somewhere between the silly and the cynical: silly because civil rights are so obviously basic to all our lives, and cynical because there should be no need for special discussion when they are applied to the disabled. Civil rights are, after all, the treasured heritage of all of us, and they are safeguarded by the Constitution and by the Bill of Rights.

In my discussion tonight, I will first consider some major problem areas affecting the civil rights of disabled persons. Next, I will discuss the important laws affecting those areas. Finally, I will present a few cases I have been involved in through my work at Untapped Resources. I think you will find them of special interest.

One of the largest problem areas affecting the disabled is that associated with architectural barriers and inaccessible transportation facilities. Architectural barriers include steps, curbs, revolving doors, elevators too small for wheelchairs, etc. Inaccessible transportation facilities include most public transportation at the present time—buses, subways, trains, and planes. Because of these problems, many disabled are in effect barred from health care facilities, educational institutions, government offices, and courts—to say nothing of recreational and cultural facilities. We are faced with the sorry spectacle of withering independence and blighted lives as a result of social indifference, ignorance, and even hostility. For, implicit in the problem of barriers is the denial of certain fundamental rights—the right of assembly, the right to seek redress of grievances by petitioning one's government, and the right to due process—because courtrooms are among the public facilities that are inaccessible. Also involved are the denial of appropriate education, gainful employment, and adequate health care, and exclusion from the enjoyment of attending concerts, the theater, movies, and a host of other recreational services and facilities.

The issue has not lain dormant. Congress is not unaware. The problem of denial of access was addressed in a 1967 Senate report (No. 538) to the 90th Congress:

> There are approximately 22 million people in the United States who because of some form of physical handicap are restricted in their ability to move from place to place.... The Federal government, in the past, has literally locked out millions of its citizens from the public buildings.... These people constitute a tremendous asset of our country which is not being fully utilized.... It is of little use to find employment for an individual confined to a wheelchair if he cannot get up to, or through, the door of the building, or if he cannot get a drink of water or go to the toilet after he is inside the building. ["Is the Constitution Handicapped?" p. 6]

The point could be made more overwhelmingly. In the case of *United States* v. *Guest* (86 S. Ct. 1170 [1966]), involving the issue of state responsibility to its residents, the Supreme Court made the following points:

1. The Fourteenth Amendment applies to a broad area of state responsibility, the limits of which are difficult to define;
2. In connection with the individual, the involvement need not be either exclusive or direct; and
3. Rights under the Equal Protection Clause may well be created even though the participation of the state was peripheral or its action was only one of several cooperative forces leading to constitutional violations.

Let me try to amplify the third point. Imagine twenty-four people in front of a state building, twelve of them the so-called nondisabled and twelve disabled who would have difficulty negotiating the barriers leading up to the building—for example a flight of steps or a steep ramp. The fact that the building was made and created solely for the use of those who can easily get in it, the so-called nondisabled, while others, the disabled, could not get into it—that is a violation of the Equal Protection Clause. It is a blatant example of exclusion, and it is therefore impermissible. This is what the Court meant when it said that rights under the Equal Protection Clause may well be created even though the participation of the state was peripheral. When the state's architects constructed that building they may not have thought about disabled people. But the state has to think about all its citizens.

The Court's ruling in *United States* v. *Guest* is applicable to the plight of the disabled who are denied access to a state building, because it can be argued logically that state *inaction*, as well as state action, may constitute a violation of the Equal Protection Clause. I submit that the denial of access—a cornerstone problem is acknowledged in the Senate report quoted earlier—is violative of both the spirit and the intent of constitutional civil rights laws.

Now let us consider some of the laws affecting the disabled. In an article published in *Programs for the Handicapped* I wrote the following:

> But what of law? The phrase "law and the handicapped" too often points to the failure of society to protect the rights of the handicapped. Yet the law constitutes a major resource to which the physically handicapped *must* turn if their rights are to be affirmed and/or established.

And later in that same article:

> In most instances the physically handicapped . . . resign themselves to an existence . . . materially and sociologically unproductive to themselves, their families, and society in general. . . . Even if their inclination is not to withdraw from society, the task of seeking aid and assistance to which they are legally entitled is so monumental and frustrating that it discourages and disheartens the vast majority of those who even attempt it. Untapped Resources (the not-for-profit comprehensive legal service which I am pleased to represent) believes that the law must deeply confront the poignant question: Why is it that the physically handicapped constitute a class of untapped resources?

That article was published in July 1976. I believe that the points it makes are still valid. Although there has been increased public awareness that disabled people are possessed of civil rights, I still find a disturbing percentage of disabled people who are loath to assert their rights.

Let us begin our brief overview of significant laws affecting the rights of the disabled with the Rehabilitation Act of 1973 as amended (PL 93-112). In the original act, Congress defined the term "handicapped individual" solely in connection with employment. In the 1974 amendment, Congress defined the phrase much more broadly, as follows:

> Any person who (a) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (b) has a record of such an impairment, or (c) is regarded as having such an impairment.

Congress clearly sought to forbid discrimination against all handicapped individuals–regardless of their need for or ability to benefit from vocational rehabilitation services.

This particular act represents the first federal civil rights law protecting the rights of so-called handicapped persons; it reflects a national

commitment to end discrimination on the basis of handicap in the following significant areas: architectural and transportation barriers, health care, education, and employment. However, while the legislation raises hopes that the civil rights of the disabled will be affirmed, it does not back them up with vigorous enforcement. It may be likened to a diamond in the rough. Lawyers contesting cases under this act must be prepared to use it only as a tool and not regard it as a finished product. Nevertheless,the disabled beneficiaries of the act must be prepared to assert unflinchingly their rights under the act.

Substantive rights as contained in the Bill of Rights–the right of assembly, the right to seek redress of grievances by petitioning one's government, and the right to due process–are all implicitly and explicitly protected in this piece of omnibus legislation. Because implicit in each of these rights is the right not to be excluded from a building in pursuance of those rights by reason of architectural barriers. The Architectural Barriers Act (PL 90-480) in broad terms forbids architectural barriers in buildings, wherever built, that are financed in part or in whole by the federal government. Although passed by Congress in 1968, provision for enforcement was not made until the Rehabilitation Act of 1973, under which the Architectural and Transportation Barriers Compliance Board was established. As a recent member of the advisory committee to the compliance board, I can say with some confidence that we are at least beginning to bare our teeth.

The right to assembly: A New York State law–companion to the 1973 act–called the Public Officers Law (L. 1977, Chap. 368)–became effective September 1, 1977, and contains two significant sections:

> 93 (b) Public bodies shall make or cause to be made all reasonable efforts to ensure that meetings are held in facilities that permit barrier-free physical access to the physically handicapped. . . .
> 74 (a) It shall be the duty of each public officer responsible for the scheduling or sitting of any public hearing to make reasonable efforts to ensure that such hearings are held in facilities that permit barrier-free physical access to the physically handicapped. . . .

Both of these sections are keyed in with the state's Public Buildings Law, which (in Section 50, Subdivision 5) defines physical handicap as follows:

> (a) impairment requiring confinement to a wheelchair; or
> (b) impairment causing difficulty or insecurity in walking or climbing stairs or requiring the use of braces, crutches, or other artificial supports; or impairment caused by amputation . . . or other ills rendering the individual semiambulatory.

The right to petition one's government for redress of grievances: Sections 503 and 504 of the Rehabilitation Act of 1973 establish the disabled person's right to challenge the government, particularly as regards health care, employment, education, and access. Hence, grievances in these areas are susceptible to redress by the government upon proper petition. Again, the troubling consideration—probably silly, certainly cynical—is that we widely hail the 1973 act, especially Section 504, as the *first* civil rights act protecting the rights of the disabled. It was not the first. Enforcement has been the problem—and it still is. There has to be more than a baring of teeth when it comes to enforcement. Disabled people must forthrightly emerge and insist that their civil rights be enforced. Otherwise, the legislation will mean nothing.

There are other companion state laws to the act of 1973. In New York, for example, there is the so-called Human Rights Law of the State of New York, which is found in Article 15 of the Executive Law. It forbids discrimination against the disabled in the following areas: health care, education, employment, credit institutions, housing, and access to public accommodations.

Due Process: Underpinning all of the rights we have been discussing, and essential to the disabled asserting those rights, is the elemental factor termed "due process." Due process requirements involve adequate notice, in the sense that one must be notified of any diminution or increase with respect to entitlement to benefits or services. Due process also means that in the case of a dispute concerning the right to entitlement of benefits or sevices, there should be a fair hearing regarding the conflict that has arisen.

Underscoring due process, and especially applicable to the rights of the disabled in this regard, is the Supreme Court's finding in *Goldberg* v. *Kelly* (90 S. Ct. 1011 [1970]). The Court made the following points in that case:

1. That termination by a state or a lawful benefit or service is a state action requiring procedural due process.
2. As a matter of constitutional law there must be afforded an opportunity to be heard in terms of the various limitations by which the complainant is affected through no fault of his or her own.
3. There must be no insistence in such due process proceedings upon written presentation only, since written presentations do not provide the flexibility of an oral argument.
4. Basic rights adhere in the due process procedure and care must be taken to assure confrontation and cross-examination in almost every setting where important decisions turn on questions of fact.
5. Without question the right of legal counsel is basic to the meaning of due process.

These are important ingredients to consider in pursuing the rights of the disabled, and it is essential to remember them. Law for the disabled should not be a cosmetic concern for significant human rights, nor should it be an overbroad statement generally incapable of being quickly followed up with implementing rules and regulations. Much of the law relating to the disabled tends to be wanting, leaving in its wake a rubble of uninformed decisions. The challenge is thrown back upon disabled persons themselves to see that broadly based laws protecting their rights are clearly defined and shaped into a cohesive, significant pattern that properly reflects the reality–that the disabled are preeminently whole human beings with certain rights that must be adequately protected.

In closing I would like to share with you some details of our work at Untapped Resources. The picture behind me–an empty wheelchair at the foot of the imposing steps of the U.S. Supreme Court–symbolizes what we are up against. It is a silent but telling rebuke of a hostile society that bars, with architectural barriers, the entrance to the place where justice ultimately sits.

The legal problems of the disabled are compounded by failure on the part of all who should know better–including many disabled–to comprehend the complexities involved. That is what we mean when we describe our work as being, in part, "comprehensive legal services."

At Untapped Resources we prefer to negotiate rather than to litigate. Negotiation triumphed in the first of the legal matters I shall discuss with you in which Untapped Resources has been involved. Representing a disabled client necessitated our seeking injunctive relief in the New York State Supreme Court located at 60 Centre Street here in the city. When first I went to the building housing this court, I was confronted by steps leading into the building. At the judges' entrance there was but one step–still an architectural barrier for me. I protested and was told in effect to take it or leave it. Fortunately, that particular case was settled before it came to a court confrontation. Well in advance of the next time I had to appear in the same court for a different client, I made it clear in writing to the State Office of Court Administration that the condition of inaccessibility was unacceptable and an affront to federal and state constitutional law. Negotiation began. Today that court is accessible, and other architectural barriers within that building are in the process of crumbling. We were able to avoid the certain litigation that would have followed if firm but tactful action had not been taken.

Another case: A celebrated disabled person in this state had been abusively treated by one of the branches of the Office of Vocational Rehabilitation (OVR). This agency is, as many of you probably know, heavily funded by the Department of Health, Education, and Welfare and is therefore subject to the regulations of Section 504. Despite the controlling force of Section 504, the attorney in my office who was directly involved in this case was flatly told by the agency person in

charge that we would not receive any cooperation from OVR and that our client's records would not be made available. Worse than that, there was a clearly retaliatory attempt to cancel a contract involving life-support services for our client. Rather than rush into litigation on behalf of our client, we chose the negotiation method and substantially resolved the problem by speaking with and writing to someone higher up the ladder in that agency. All of the problems just referred to have now been satisfactorily resolved.

As a quadriplegically disabled person I am particularly sensitive to the problem of dependency needs and hospital policies. One of our clients, a quadriplegic in a well-known rehabilitation facility in this state, was denied the right to around-the-clock individual attendant services, which services were to be paid for by a separate, outside agency. The physician's rationale for the denial was that the proper rehabilitation posture in our client's case was to bring him to a "reality of his dependence" by forcing him to fend for himself, virtually without assistance. The physician was supported in this view by the director of the facility. Their resistance was firm; our client was, to put it mildly, agitated. Untapped Resources had nearly exhausted its negotiating resources, and time was of the essence, because serious health problems were involved. Public attention was focused on the problem through the good offices of a concerned newspaper reporter. A confrontation of relevant parties was held, approval of the attendant care was granted, and we hope that such a problem will not again arise—at least in that institution.

I submit that the title of this lecture is a misnomer. Because the rights of human beings, disabled or not, are inviolate. My remarks are not intended to be a lecture on morality; they are intended to focus the attention of each of you toward a challenge of our times—a challenge aptly referred to by the seventeenth-century poet John Donne:

> No man is an island entire of itself
> Every man is a piece of the continent, a part
> of the main.
> If a clod be washed away by the sea
> Europe is the less;
>
> Any man's death diminishes me
> Because I am involved in mankind.
> Therefore, never send to know for whom
> the bell tolls
> It tolls for thee.

PANEL DISCUSSION

Panelists: Randi Baker, Baruch College
Ethan Ellis, Office of Advocacy for the Developmentally Disabled of New Jersey
Barbara George, Caldwell College

Moderator: Frieda Zames, New Jersey Institute of Technology and Disabled In Action

MS. BAKER: Until recently I was involved in the Teachers College Project for Handicapped College Students, working with colleges in the New York City area. Primarily, my work was to help colleges conform to the accessibility requirements of Section 504, and it gave me some experience with that piece of legislation. I have now accepted a job as associate director of the Baruch College Computer Center for the Visually Impaired.

Talking about civil rights and accessibility, one right that visually handicapped people do not have is easy access to information of the nature that most sighted people find readily accessible—such things as bank statements, course syllabi, and birth control information. Our center, the Baruch Center for the Visually Impaired, attempts to bridge this gap and to make accessible a great deal of information through the use of braille automation—producing braille by use of computer.

We are also trying to make education in computer professions accessible to visually handicapped people through the use of modern technology, by imitating existing technology with new equipment that has been devised. I think that we have one of the largest collections of educational equipment for the visually impaired that is currently in existence. We are a new center, and we have a lot of growing to do, but we have a lot of dreams about accessibility and civil rights, and that is why I am here.

MR. ELLIS: Our office was established in the New Jersey Department of Public Advocates, which is an unusual cabinet-level office whose commissioner has the authority to take to court any bureaucrat in the state—and by implication his boss; also any cabinet officer who impedes the public interest. We have that same authority in our office. We were established under Public Law 94-103, known as the Developmentally Disabled Bill of Rights, in order to protect and act as advocate for the rights of the developmentally disabled. Our program concentrates on that group, although we have other programs within our office that deal directly with the Division of Vocational Rehabilitation; and our mandate is somewhat broader than our name implies, in that we do take cases of people with other diagnostic disabilities.

I am surrounded in the office by five attorneys. I am not myself an attorney, although I think in a few years I will be able to hang out my shingle in Philadelphia, just by having the experience rub off on me.

We use the legal approach when that is necessary; like Mr. Brewer, we prefer to negotiate if that leads to practical results. So far we have handled 300 complaints and have been able to resolve all but 10 of them without having to go to court. One of the things I learned when I began associating with attorneys is that they prefer not to go to court if they can avoid it, and we have been successful so far. I would like to say that the cases which have taken us to court are those that involve money and not goodwill. We can educate people to goodwill; we can not educate them to be willing to spend money. When the process of education breaks down, then we are forced to go to court. I could talk endlessly about the 300 cases we have handled so far, but I will stop now and let others have a chance to speak.

MS. GEORGE: I am a member, and presently the recording secretary, of Disabled In Action for New Jersey. I am a psychology major at Caldwell College, graduating this May, and have been very busy becoming active in disabled groups—this year with Disabled In Action. I was a panel participant at the first annual New Jersey National Rehabilitation Association Convention. The panel discussion was on consumer advocacy, which I feel is the essential focus of our civil rights struggle; it cannot be emphasized enough how much you have to advocate and be assertive to get these rights and to keep these rights alive.

Also, the New Jersey Division of Vocational Rehabilitation has appointed me as a member of their statewide Consumer Advisory Committee.

DR. ZAMES: I am going to say a few words about Disabled In Action (DIA) of metropolitan New York and about civil rights in general.

DIA is a civil rights organization of people with all types of disabilities. As an activist civil rights group, DIA makes use of the following techniques, among others. First, we negotiate with public and private officials on specific issues. We have been and still are negotiating with United Cerebral Palsy (UCP). We also have representatives on the Advisory Committee to the New York City Task Force on Transportation for Elderly and Handicapped Persons, and we are negotiating with New York City transportation officials. The biggest nut to crack is the Metropolitan Transit Authority. Second, we initiate class action suits. Several members of DIA were co-complainants in the transbus law suit. This suit resulted in Transportation Secretary Brock Adams mandating the transbus, which is a low-floor, wide-door, ramped bus; after September 30, 1979, this will be the only type of bus that can be purchased with federal funds.

We try to raise the consciousness of disabled people and others via the media and demonstrations. For example, we have a radio program called "Disabled In Action Speaks" on WBAI (99.5 FM). Also, we have been involved in several demonstrations. We demonstrated twice against the UCP telethon, and we participated in the sit-in at

26 Federal Plaza in support of Section 504. That helped get the law passed.

We also help enforce legislation that already exists. For example, although Section 504 is potentially a very powerful law, it is up to us to make it effective. I attended a 504 workshop in February, and there I learned how to use the regulations and how to encourage institutions to come into compliance with 504. I would like to explain to you briefly how you can use these regulations. First, you must read and understand the regulations thoroughly, especially those parts that pertain to your institution. Second, find out who is the 504 compliance officer for your institution. Third, ask for a copy of your institution's transition plan. This is a mandated document, which should have been submitted to the Compliance Board by December 2, 1977. Also, ask to become a member of the 504 compliance committee–which is supposed to draw up a transition plan if one has not yet been drawn up, and to complete a self-evaluation process by June 2, 1978. These are the steps you should take to bring your institution into compliance. We have copies of the Section 504 regulations here, and you may come up and get them if you wish.

I believe that changing the name of the Vocational Rehabilitation Act of 1973 to the Rehabilitation Act of 1973 indicates a significant philosophical change of attitude toward people with disabilities. For the first time we were recognized as a class that was discriminated against, and for the first time the mandate against discrimination applied to all disabled people, not only those who were employable. This does not mean, however, that a disabled person is not expected to be qualified for the job or educational program he or she seeks. In fact, the regulations contain three definitions of a qualified handicapped individual, definitions that relate to (1) employment, (2) public school education, and (3) post-secondary and vocational education.

To conclude, I believe that we who are disabled must become more political as participants in the disability rights movement. We must demand our rights, and we must join forces with the civil rights movement and the women's movement. We must learn from these movements how to get power and how to use it. A few of us from DIA took part in the demonstration in Washington against the Bakke decision. We were often asked why we were there; other demonstrators were surprised to learn that affirmative action is an important issue for us. Unemployment is so high in the disabled community that we are not even counted in unemployment statistics. Actually, many people are shocked to learn that we can and want to work.

I would suggest that we demand that at least half the staff–especially the policy-making staff–for all programs dealing with disability and disabled people consist of people with disabilities. No other discriminated-against class would tolerate their programs being run by other people. This way we would begin to obtain the power to control our own lives.

QUESTION: An official at Long Island University said that program accessibility does not necessarily imply a barrier-free environment. Would anyone care to address that issue?

MR. BREWER: Program accessibility means that if a course is being offered in a building that is inaccessible, the college is required to move the venue of the class. There must not be any segregation of disabled people into a separate classroom, because that is one of the most horrendous insults to disabled people.

There is a story in the law literature about a disabled student who was assigned to a room—one room, by himself—because allegedly he could not get into the other buildings on the campus. But Section 504, which as Dr. Zames says is a powerful tool, forbids that kind of discrimination. We are not some kind of unacceptable human being who must be segregated.

MS. BAKER: It is not just Long Island University, a lot of other schools have these problems too. I would like to ask what particular areas you feel are not accessible to you that you would like made accessible.

QUESTION: The bookstore and the registrar.

MS. BAKER: That is program accessibility—unless they are sending someone to the bookstore for you. There is something in Section 504 about the things institutions have to do by 1980 and the things they have to do right now. It has to do with the problem of financial strain on the university, with whether making a particular service or facility, such as the bookstore, accessible will put an unreasonable strain on the institution's resources. If so, the legislation says that disabled students must get by somehow. But I would say that the bookstore is among the basic things that all other students can get to. You said the bookstore and what else?

QUESTION: The registrar and the admissions counselor. They come to me.

MS. BAKER: Then as far as my understanding of the legislation goes, they are complying with the law. But referring to what Mr. Brewer said, in a sense you are being segregated from those activities, and I do not know how Section 504 is going to be interpreted in such matters.

DR. ZAMES: A lot of this accessibility costs a great deal of money, and in fact institutions are thinking just the opposite of you—they think they have too little time. I think that in some areas—not so much accessibility but in some other areas—the government's attempt to

gain compliance, the institutions' need to comply, is very hasty, especially in public school education; there are a lot of problems with the timing. Program accessibility, by the way, is supposed to have taken place already. Architectural accessibility is given until 1980; but the institution is supposed to have a plan—over a three-year period—explaining exactly what will be done and when. This is a big step. If you can get deadlines mandated, you have come pretty far.

MS. BAKER: I would like to add something to that. You should demand to see your school's compliance plan. I think you have the right. I have seen some of these compliance plans. I saw one at a major school in this city that was four pages long. Four pages! And then it was made to look more substantial by putting the regulations themselves in the same folder. You should demand to see those plans. You should demand to seee what they are doing.

DR. ZAMES: You think four pages is bad, Long Island University's plan is one page long. I saw it, and it was obviously written in about half a day. I think you should obtain a copy of the regulations and read them very carefully. There is a special portion on colleges. I think you should get to know the regulations so well that you know them better than the administrators. Then you can beat them at their own game.

QUESTION: Why is there a separate law for the developmentally disabled as opposed to people with other disabilities?

MR. ELLIS: The reason is that political pressure was brought to bear by that group to get such a law passed. I think this illustrates, this provides a platform for me to address, a couple of the earlier questions. Getting laws on the books is the first step in achieving rights. But it is a very short first step. A law, as one of the attorneys in my office says, is just a prediction by a group of legislators about how a judge is going to react when the case comes to court. We now have some statutes on the books, including the Developmental Disability Services and Construction Act (D.D.)—and a bill is currently before Congress that would extend the D.D. Bill of Rights to all severely disabled people.

The rights and the regulations that we have under Section 504 will not do us a bit of good until we get out and insist that those regulations be carried out by the general public. Those regulations have to be tested in court before we know what their full meaning is, before we truly know how they will benefit us, before people understand that there are teeth in those regulations. I was shocked and amazed earlier this week. One of our attorneys came back from an orientation session held in the New York City Office of Civil Rights, Region 2, and reported that when he asked what steps that office, which has the major responsibility for administering Sections 503 and 504, were taking to enforce

those regulations in individual cases, he was told, "None, we refer them to Washington." That suggests to me that we must use all of the tools at our disposal—not only litigation but community organizations and the media. As has been mentioned by both Mr. Brewer and Dr. Zames, we must learn how the political process works and how we can get involved.

I have had the opportunity, while I have been on this job, to see how the developmentally disabled advocates lobbied to get the D.D. Bill of Rights passed in 1974. They have all learned their politics, and they practice it intensely. I was not not part of that operation when the effort got started, and I have gained an enormous amount of respect for those individuals. But I sometimes disagree with that whole movement because it suggests a division among disabled people that I consider politically counterproductive. It behooves us, if we are going to have a movement, to avoid ways by which we are divided into groups that individually cannot command any attention.

That answers, I think, several questions and certainly addresses what you must do with the reluctant compliance board out at Long Island University. They will respond to a carefully thought out plan—one in which you not only deal with the regulations but use strategies to which they are vulnerable. And they are vulnerable to a variety of strategies, such as calling issues to the attention of the general public through the media. We need to learn these strategies. We are in a very good position to execute them if we do learn to use them, because we are visible. We may not like being visible under ordinary circumstances, but when it comes to making a point, that can be to our advantage. As Joe Namath says in the commercials, "If you've got it, flaunt it." So, let us learn how to do that.

DR. ZAMES: I am not sure whether you mentioned this: There is an amendment being considered in the Senate on this issue. Title II would repeal the Developmental Disability Services and Construction Act. In its place is proposed a larger "severely handicapped" act, broadly defining the term and containing no reference to age at onset of the disability. So I think that there is a tendency now to go in a different direction.

QUESTION: I would like to ask Dr. Zames why she brought up the women's movement and the Bakke case. Introducing the women's movement and the Bakke case, which are controversial issues, into the disability rights movement would tend to divide us rather than unite us.

DR. ZAMES: My position is that the 504 legislation practically imitates Title VI and Title IX of the civil rights law. Title IX has to do with women. All three groups—minorities, women, and the handicapped—are civil rights groups; they are groups that have been discriminated against. We have that problem in common. When I was at the Bakke

demonstration, the cry was racism and sexism. No mention was made of what we call handicapism. We are not even known about, we are not seen as a civil rights group. We are not seen as a group that needs affirmative action. I think we have to be seen as such. Women and racial minorities are seen as groups that are discriminated against. We are seen as a group that needs help; we are not seen as a group that struggles with inadequate laws or with discrimination. And I think that is why we have to join with them. We have to become political. And I think we have to become radicalized. Not everybody agrees with me, but that is what I think. We are not going to get power by staying by ourselves. We are going to get power if we join with other groups. That is my position.

QUESTION: I do not see why we should join with the so-called women's movement. I do not even agree with that movement.

DR. ZAMES: I think the point to be made here is that there are many groups of disabled people. People join the group they are most comfortable with. Or they do not join any group.

QUESTION: How do you know whether an institution comes under the 504 regulations?

MR. BREWER: The 504 regulations are limited to those institutions or facilities that are receiving federal aid including funding from the Department of Health, Education, and Welfare—that could be a school or an organization—as opposed to those who have been awarded a federal contract, which would come under 503 for the most part.

QUESTION: I went to take a tour of *The New York Times*, and they told me that because I was blind it would be unsafe, and they would not let me on the tour. Do I have recourse to 504 in this case?

MR. BREWER: *The New York Times*, if they receive money under assistance provisions or any kind of funding from the Department of Health, Education, and Welfare, would be subject to the 504 rules. The answer rests upon how they get their money. Do they get any money from the Department of Health, Education, and Welfare to assist them in their function? Ask! My Lord, there are about 500,000 or more different types of operations in this country that receive money from the Department of Health, Education, and Welfare. I doubt, frankly, that *The New York Times* is one of them. They are a profit-making concern. If they have a federal contract, the only possible cause for action against them would be with respect to employment.

MR. ELLIS: That is a problem that may be easy to solve or may not,

depending on the institution. I would start out by making an inquiry, as I think you did, in the Office of Civil Rights. If that does not work, it may require a little more research. There are a number of agencies now, both private and public, that specifically deal with the problem of relating the law to the handicapped. The National Center of Law and the Handicapped is one. There are several others. Each state has one of these protection or advocacy agencies for the developmentally disabled. They could do that kind of research for you even though you do not fall under the general category as a potential user of their services.

One method you might use, for example, is to take a look at the annual reports of the corporation. You may not want to do that sort of thing yourself. Should a question like that come to our office we would go through a number of research procedures until we found out, one way or the other. It is difficult for a private person to find out this information if it is not available from a public agency, and in a case where you cannot find it, I would try to locate a public interest law firm of some kind, not necessarily one that is dealing specifically with the disabled. The Public Interest Law Center of Philadelphia is one that would handle that. I am not as familiar with the ones in New York as some of you who are natives may be.

MR. BREWER: I do not think that you will find relief under Section 504. But if you were denied prejudicially the right to tour *The New York Times*, that would be considered discrimination impermissible under the Human Rights Law of the State of New York, and you could call up the Human Rights Law Division and tell them that you were discriminated against. You have a clear case there, but not under 504.

QUESTION: Can we look forward to a general law center like the Public Interest Law Center of Philadelphia, here in New York?

MR. BREWER: That is an interesting question. When I was on the board of directors of the National Center for Law and the Handicapped, we polled many of the universities in this area because we were thinking of relocating to New York. The universities and the law schools did not feel it was their cup of tea. There is, however, under the Community Action for Legal Services, a new unit that is about to organize called the Handicapped Persons Legal Support Unit, and their number is 925-1000. Then of course you have the Office of the State Advocate for the Disabled, which is down at 2 World Trade Center. As to the specific question of whether or not we are going to find a group in New York burgeoning forth into a powerfully committed law office for all disabled, I frankly doubt it; because the foundations that give money and the corporations that give money have not been rushing to the front to support legal services for the disabled.

QUESTION: The American Civil Liberties Union (ACLU) has handled one case, and they are now handling mine. They are interested in cases that will set precedents and bring general change.

DR. ZAMES: The New York Civil Liberties Union (NYCLU) has handled cases of disabled people. I think the case you are talking about has already been settled by the NYCLU. It is the case of a man who was a member of Disabled In Action, Arthur Wohl. He wanted to go on a cruise, and no steamship would let him on because he is blind, so he persuaded the NYCLU to take his case. He said it was very interesting; they knew law but they knew nothing about disability, and he had to sit by the lawyer and tell him what to do. For instance, one of the witnesses that the steamship liner managed to produce was a blind woman who testified that it is impossible for a blind person to go on a cruise. So he said to the lawyer, "Well, question her." The lawyer said, "No, I don't want to." They found out that this woman would not even go out of the house by herself. She was completely immobile, and so of course she was no judge of what was possible for a blind person who was very mobile. By the way, he won his case.

I know the NYCLU is very interested. They were not for a long time; they saw the disabled as people who required care. Now they see us as a civil rights group.

Barbara George has some publications that you can get free of charge, and she would like to tell you about them.

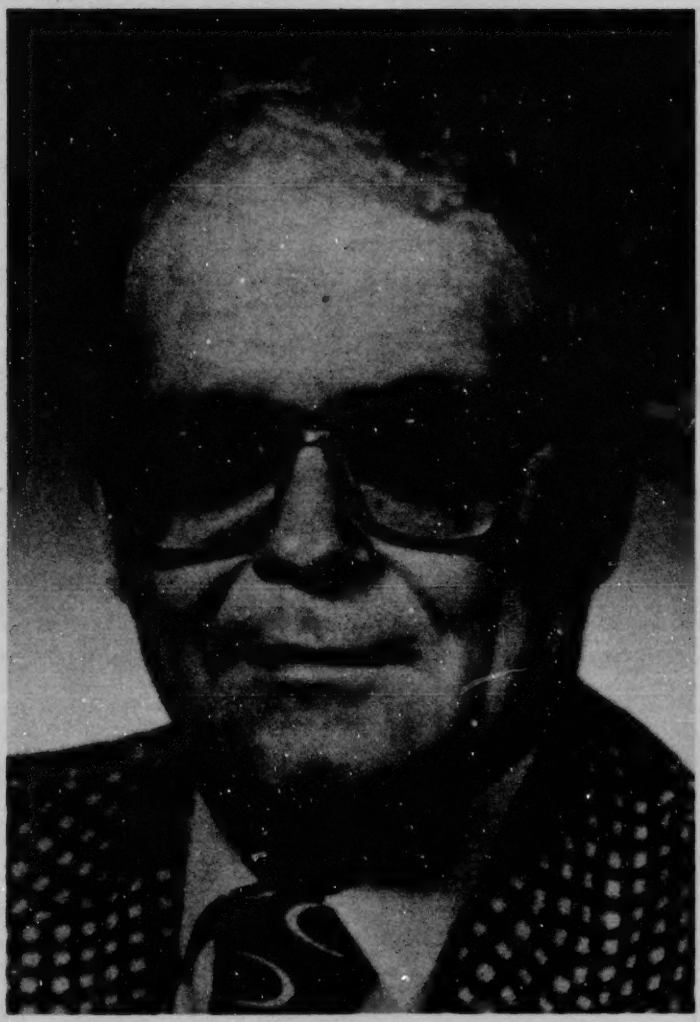
MS. GEORGE: The publications I want to mention are all published by federal agencies dealing with the civil rights of the handicapped. The first is the Office of Handicapped Individuals (OHI); the address is 338D Hubert Humphrey Building, 200 Independence Avenue SE, Washington, D.C. 20003. OHI puts out a bimonthly publication about programs for the handicapped, and although it is primarily written for administrators, I feel it is equally beneficial to the handicapped individual who is not an administrator. The second agency is the National Center for Law and the Handicapped, which publishes a magazine called *Amicus*. It is also bimonthly, and can be subscribed to at the agency's address: 1235 North Eddy Street, South Bend, Indiana 46617. The September 1977 issue of *Amicus* had a special report on Section 504. Another issue had a special report on education for the handicapped. The third office I want to tell you about is the Architectural and Transportation Barrier Compliance Board. Their address is Room 1010 Swetzer Building, 330 C Street SW, Washington, D.C. 20024. They provide two free booklets: *Access America: The Architectural Barrier and You*, which describes the process they use in dealing with complaints and enforcing rules; and *The Resource Guide to Literature on the Barrier-Free Environment*. Finally, I would like to mention that in the state of New Jersey there is an office called the Public Advocate, which has a toll-free number in New Jersey

(648-3847). If you have any type of problem, they will take care of it.

MR. ELLIS: The office you reach at the toll-free hotline handles complaints of all citizens in New Jersey, irrespective of the nature of the complaint, and they will probably refer you to us if you call that number. If you would like to reach us directly, call (609) 292-2940. If you are a New Jersey citizen and you are calling about a case that involves you directly, feel free to call collect.

Part Four

Employment



John J. Gavin is the Director of Allergy Research Affairs at Miles Laboratories. He founded the American Association for the Advancement of Science Project on the Handicapped in Science.

Concerning Employment of the Disabled

John J. Gavin

Miles Laboratories, Elkhart, Indiana

I am supposed to talk about employment. What I want to talk about specifically is: how do the disabled get jobs, and how do the disabled keep jobs? I think that what I want to get across to you might best be illustrated by a story about Easter Island, a nesting place for turtles. One of them fell in love with a rock. The rock was shaped exactly like a turtle, and for months and months the turtle forced his attentions on the rock. Well obviously, nothing happened. The moral of the story is: you can spend a lot of time and effort, but if you fail to select the proper target then your time and effort are wasted.

What the disabled have going for them is this: the manifestations of disability are sometimes difficult for the casual observer to accept, because the casual observer looks upon these phenomena as tragedies. But those who must live within the physical limits of the disability develop a capacity to struggle and adapt. And that capacity provides the means to make life whole and coherent, even if painful and inconvenient. That is what we really have going for us: we have a reason for being, we have a reason to do a first-class job. So we can perform well under circumstances that other people may find trying; we can even do better.

But one of the things we need to do, as people with disabilities, is to try to understand—not only ourselves but the people we deal with. St. Thomas has said that of all human pursuits, the pursuit of wisdom is the most perfect, the most sublime, the most profitable, the most delightful; the proper function of man is to understand. Now this is where we often fail—not only the nondisabled but also those who are disabled. Sometimes I doubt that we, the disabled, understand or try to understand the people with whom we deal. Take employment, for example: just because you qualify for a job, just because you have the technical qualifications, is not sufficient reason for you to get the job; employment is a sort of happening. There are a lot of elements involved in hiring and firing that have nothing to do with qualifications. For example, I hire people, and in the course of interviewing a number of people, I find that some of them come in and they talk to me and they just leave me cold. It has nothing to do with their qualifications,

it has nothing to do with their personalities; we just do not relate. And conversely the same thing happens with people who are looking for jobs. Sometimes you go in and you talk to the person who is going to be your boss, or you talk to other people in the organization, and they just do not come across. You are turned off; you would never work for that organization. This reaction is something that cannot be defined or explained; and it happens more often than you might think.

Disabled people are sometimes oversensitive. There are a lot of things involved in working. You have to learn to get along with other people, or they will not get along with you. This has little to do with disability; it is simply the interaction of people with people. Deaf people have a harder time than anybody else, because they tend to become suspicious. You see two people over in a corner talking and your immediate reaction is: "What are they talking about—me?" So deaf people sometimes go around getting worked up about imaginary things. Because they are unable to understand all that is being said, they feel they are being excluded. But what we have to get across to deaf kids is that the world does not begin and end with them; there are other things people talk about. When you can adopt that attitude, then you will have a better chance of adapting to a job.

Also, you have to learn to see your problems in perspective. You have to realize that even though you are disabled, you do not have a monopoly on all the problems in this world. There are many kinds of problems. Everybody has problems. The elderly have problems—they have just had the retirement age raised to seventy because they were unhappy about having to stop working. All of these problems have to be recognized.

But above all we have to learn to have confidence in ourselves. We have to sit down and take stock of ourselves, and say, "Okay, who am I? What can I do?" This self-questioning will help you to acquire confidence, then you can go ahead and approach your job. When you look for a job, it should be on the basis of: "I'm quite good; the company is lucky if I am hired." You have to build up that confidence; you have to learn to sell yourself if you want to get a job.

At Miles, about 6% of our work force is disabled. Some of the problems we encounter with the disabled are not due to the person's disability as such but to the fact tht those who are disabled young have not had the opportunity to assimilate the things one needs to know about how to get a job, how to adapt to the working world.

Most kids when they get out of school want to go to work, and they talk among themselves: "Well, I went to this place, and this and this happened." Before you actually go looking for an entry-level job, you need to have learned, at least by word of mouth, some of the things that go into the process. But deaf kids are deprived of this kind of peer feedback because they are cut off from casual conversation. And this applies not only to the deaf. When you are disabled you are to some extent cut off, you are not fully integrated, so you are unable

to get much of this feedback. Somewhere along the line you have to learn about what goes into getting a job, becoming a worker.

One of the major problems we face is discrimination. No society can be said to enjoy freedom whose citizens do not have a full and equal share in making the laws by which they are governed. Noah Webster said that in 1785, and Peter Drucker says essentially the same thing in his statement that no society can function as a society unless it gives its individual members social status and function. In the past, human rights and freedom were defended on a more or less selective basis; but with time the nation has matured, moods and priorities have shifted. More and more attention has been given to the plight of those individuals who were casualties of a paradoxical "equality" in which the physically able, Protestant, white male was somehow more equal than other citizens. The effects of this inequity were detrimental not only to individuals but to the country as a whole. The squandering of human resources was a transgression second only to the concomitant injustice of excluding capable and competent persons from full participation in a supposedly free society.

But government by common consent provides various mechanisms through which such injustice may be remedied, and the people of this nation have seen fit to elect, over the past thirty years or so, representatives who have passed a number of laws aimed at eliminating discrimination on the basis of sex and color and handicap. Now, with the new laws on the handicapped, we have something going for us when we look for a job.

The Rehabilitation Act of 1973 is probably the most important piece of legislation enacted on behalf of the disabled in the history of this country. Section 503 of the act applies to all industries that have contracts with the government. It requires

1. Affirmative action on the part of the employer to search out handicapped workers.
2. The adaptation of jobs and of the environment to meet the needs of the disabled person. Jobs have to be structured so that disabled people can perform them. Employers must ascertain where the adaptations may be made and ensure that jobs are made available to the disabled.
3. Employers must train workers for individual jobs that lie within the general qualifications of handicapped applicants.

Section 504 states, "that no otherwise qualified, handicapped individual in the United States solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

Now, all this is good, it helps; but Sections 503 and 504 will not by themselves get you a job. There have to be other things that go with it.

The law is now five years old, and in purely legalistic terms, it has not done very well. Section 501, which deals only with government workers, is probably the least enforced section of all. As a matter of fact, employment of handicapped people within the federal government has gone down instead of up; only 27 of 112 agencies have shown any increase at all. The government should be the first to help disabled people and make sure they have jobs. If the government does not lead, there is no leader—theoretically. But industry has done a fair job by itself. If you see this legislation as a means of gently twisting arms, rather than as setting up an adversary relationship, then you can use it as a carrot instead of as a stick. And you will probably achieve more by doing so. Because there are many ways the law can be circumvented. Many of the grounds for enforcement have to do with *overt* discrimination, and overt discrimination seldom takes place. The following would be an example of over discrimination: a person with a hidden disability, such as epilepsy, may not have told the employer about it. If that person has a seizure while at work and the employer finds out and fires that person, that would be overt discrimination. About 90% of the cases adjudicated by the Office of Federal Contract Compliance have dealt with epilepsy. The law will help; you can use it, and you have it as a backup. But you need more than that—which we'll get to a bit later.

Section 504 of the Rehabilitation Act indicates that the recipient of Federal monies must make reasonable accommodations to the known physical or mental limitations of an otherwise qualified handicapped applicant or employee, unless the recipient can demonstrate that such accommodation would impose undue hardship on the operation of its program.

First, who is the handicapped individual? A handicapped individual is defined as any person who has a physical or mental impairment that substantially limits one or more of such person's major life activities, has a record of such impairment, or is regarded as having such an impairment. This definition covers just about everything that you can think of, including alcoholism and drug addiction. There are some people who think that alcoholics should not be covered under such a law. I disagree, because when you say this you are making a moral judgment. Alcoholism is a physical disability, and it should be covered in the same way as any other disability. One might even ask the question, "People who are now in wheelchairs because they spent too long at the happy hour and wound up with their car wrapped around a tree—are they handicapped?" If you start trying to differentiate the causes of disability, then you have new problems. Drug addiction obviously is a physical disability. And all disability, whatever its causes, should be covered.

The other key terms in the law are (1) qualified applicant or employee, (2) reasonable accommodation, and (3) undue hardship. The first is the simplest. As long as the term "qualified" is applied

across the board, to the disabled and the nondisabled, there is no problem. But that does not always happen. What sometimes happens is that the interviewer looks at you and says, "Well, with your disability, you can't do this and you can't do that." This is outright discrimination, because what the interviewer is doing is stereotyping you. What these people in personnel tend to do is put you in a box; and they set the dimensions of the box. Their judgments, instead of being based on your particular competencies or your particular qualifications, are based on what they think they could do if they were in your position. And that is not fair, not relevant. So, if you come in qualified, then you must put up a fight. But, first you must make sure that you are qualified.

I am presently in contact with a young blind man who would like to be a molecular geneticist. He thinks that he could be a geneticist, and I see no reason why he could not just because he is blind. Being a geneticist takes visual acuity, in that you have to distinguish colors and colony shapes and things like that. But on a realistic basis, you can hire eyes, just as you can hire ears. You can hire someone who can tell you there are five blue and six red or what have you. What you have to be able to do to be a geneticist is to understand *why* there are five blue and six red. It is the understanding that makes a geneticist, not the ability to see. What were we able to do for him? We ran into a problem. He has a B.S. in biology from a prestigious university, but he has never had a lab course. Think of that—a prestigious university not giving the boy a chance to take a lab course on the basis of his blindness. That is outrageous. You cannot be a biologist unless you have had a lab course. What we have done is to arrange for him to work in a lab, and hopefully one of these days we will have that molecular geneticist who is blind but is pretty good at his job.

Reasonable accommodation: well, reasonable accommodation is somewhat more difficult. How do you define "reasonable"? For example, there are two things you can do to accommodate the disabled deaf. I have a secretary, and when I am on the phone she sits opposite me, using a second extension of my line. She repeats everything the other party on the line is saying, and I lip-read from that. That is how I use the telephone. Another way is to get a teletypewriter (TTY). But the difficulty with a TTY is that not everybody has one, and unless the other party has one you cannot communicate very well. So the question is, what should be regarded as a reasonable accommodation? Having to make someone available from whom you can lip-read across the telephone would seem to be reasonable. Having to acquire a special machine that only a few people—probably only those who are also deaf—can use may not be considered reasonable. At Miles we have a blind man working as a computer programmer. The company has provided him with an opticon device so that he can read memos and other printed materials. They have also provided reel-to-reel recorders and braille paper, and he does very well.

There are other types of accommodation, such as changing the work surface to the required height. If you are in a wheelchair, for example, a chemistry bench, instead of being at the usual height, can be adjusted so that it is low enough for you to work at comfortably but high enough for the wheelchair to fit under it. Or the problem can sometimes be solved another way, as was done for a young lady at the University of Wisconsin who has a Ph.D. in biochemistry. She is a short person, and her problem was that she could not reach up to the bench nor could it be made low enough for her. So her husband made her a sturdy little ladder, and she does well with that.

Why I am telling you all this is that when you go looking for a job, you will be asked, "How are you going to do this?" Well, you had better have an answer. Because if you do not, the employer will then have an excuse not to hire you. That is why you have to be sure: Can you work in the lab? Can you work in the office? Can you do this or that? If there is a problem, then you have to sit down and figure out how you are going to resolve it. Once you have resolved the problem, then you can go looking for the job.

Now for "undue hardship." Undue hardship is one of those qualifying clauses written in to make sure the bill would pass without too much difficulty. It is really the Achilles heel of the whole thing. Because if an employer can claim that it would cost him too much money or would be a hardship, then accommodation can be avoided. So, what is the best way of dealing with this problem?

First of all you have to be selective. If your disability is one that requires only minimal accommodation, then you can approach a wider range of employers. But if you need real accommodation, then you do not go looking for a job with a firm that has perhaps only ten employees. Because such a firm is usually not able to make the accommodations. You must look for a job with an employer who can make whatever changes are needed—one who has the money and the means to do it. If you just go around and bang on every door, you are going to have a hard time. But if you sit down and think things through, then you are going to succeed.

Career planning is another thing people without disabilities already know about. They set an objective and they plan out what they will need to do to reach that objective at some point in time. We have to do the same. We may be a little slower, but we have to have some idea of where we are going and how we are going to get there. You must put time into this if you want to get a job. These things are very important.

As I mentioned earlier, looking for a job is a happening, and you have to be prepared for everything that might come up. You have to make sure that there are no grounds on which you can be reasonably turned down. But by the same token, you should avoid getting yourself into a situation where you are in over your head. You have to be realistic as to what you can do and what you cannot do. It is traumatic

to be fired, whether you are disabled or not. But there is no reason why disabled people whose performance is below par should not be fired.

Why do I feel it necessary to say this—that there is no reason why disabled people should not be fired? Because people feel sorry for us, they do not want us to fail. But everyone needs to fail. The only way you learn in this life is by failure. How else do you learn what not to do? By making mistakes as you go along, you learn not to do this, to do something else. We must, as a basic right, have the opportunity to fail. Because if we do not fail, we do not learn anything either. If you are in the kind of a job where everything looks rosy and the going is too soft, you had better be careful, because when the going gets tough, you are the one they will do away with—and they will have a reason.

Now that we know we have the government behind us in most cases, we can at least try for jobs. If you present yourself, the employer has to listen to you. That is a big advantage. No one can turn you away. And if you can get one foot in the door, you have a chance to get the job.

It is strange, really, that there is so much reluctance on the part of employers to hire people. Just about every company that has had any experience with disabled people has nothing but good things to say. Disabled people are good workers. The basic study in this particular field was done at DuPont, which at the time of the study had 1,342 disabled people working for them. Called "The Able Disabled," the study was published in *ChemTech* in December 1974 and indicated that in comparison with nondisabled persons, over 90% of the people classified as handicapped were average or above average in job performance; 79% were average or above average in attendance; and about 96% were average or above average in their safety record. That is a very creditable showing.

The study also compared workers on the basis of job group. Among professional and technical workers, 52% of the handicapped were above average; among office and clerical workers, 40%; among operators, 30%; among craftsmen, about 28%; among service workers, about 26%; and among laborers, about 19%. By disability, people with seizure disorders did best, followed by people with hearing impairment short of total deafness, amputees, people with vision difficulties other than actual blindness, and so on down the line.

So, when you walk in, interested in obtaining a job, you should have self-confidence, knowing that the majority of disabled workers are performing well.

If we want to achieve successful integration at every level, we have to try to instill some idea in the minds of the people who hire us about what our problems are and what they are not. A person's mind expands to a new idea; it never goes back to its original dimension. So we should always try to stretch people's minds; we should push and pull. Start with the people who get jobs for us, and convince them that we can

do things, that we can do almost anything, then keep these ideas expanding.

This is where we are at present. Every week is National Employ the Handicapped week. There is a constant need for creative and talented individuals at every level of every organization. If you plan, if you look carefully into the circumstances, if you can adjust, then you too can have a job. On every possible occasion, human uniqueness and the importance of utilizing the full range of human differences for the resolution of problems must be stressed. Novel approaches to complex problems are more likely to come from a group of people with diverse backgrounds and experiences than from a group in which conformity is dominant.

Before I close, I want to tell you about two philosophers. William James, a philosopher-writer at the turn of the century was convinced that to be successful all one really needs is to be able to cope. He believed that the decisive elements in success are not intelligence or strength or wealth but will and interest—the effort one is willing to make. If we are willing to make the effort, we can succeed. Albert Camus's philosophy was that as long as man is doomed to live, he should assert his humanity and rebel against the prevalence of injustice. So if we adopt the philosophy of William James for ourselves and can persuade employers to adopt the philosophy of Albert Camus, then we too shall overcome.

PANEL DISCUSSION

Panelists: Myra Ann Bachman, C. W. Post College
Ellen Fadden, Associated Merchandising Corp.
Nansie Sharpless, Albert Einstein College of Medicine
Judith M. Warner, Consolidated Edison of New York

MS. WARNER: First let me tell you why I am here. Con Edison is probably one of the largest companies you know, though you might not be aware how large. With 25,000 employees, we are the second largest employer in New York City, 5,000 of these people are in management positions; the others are in weekly or unionized positions. Every type of employment you can think of can be found in Con Edison. Since 1963 we have employed over 2,000 disabled persons. We have also retrained hundreds of our own people who have been disabled on the job. With regard to employment of the disabled, our company is representative of what is happening in industry. Before 1973 we employed the disabled because it was the nice thing to do. After 1973 came the second phase—we employed the disabled because we had to. Right now we are the in the third phase—we are actively reaching out to the disabled because we want to employ them. And that is what I want to talk to you about.

We have actively set about trying to understand the problems of the disabled and to make all the necessary accommodations that will

enable us to place people in positions that will make use of their creativity, their talents. Our aim is to focus on their abilities, not their disabilities. We think that if we can share our experiences, both positive and negative, you will have an idea of what an industry such as ours is able to do for you. Dr. Gavin made a very good point. You have to be aware of what you can do, what industry expects from you, what you can expect from industry. And there are many things that industry can do—even a company as conservative as Con Edison. Every utility company, by its very nature, has its parameters already set. If we, a non-growth industry, can make accommodations, what about all the other large corporations in this country that are steadily growing and expanding? How are you dealing with them, how are you approaching them? These are some of the things I would like you to question me about.

DR. SHARPLESS: I have been asked to participate in this program because I am a handicapped scientist. I am completely deaf, and the thing that bothers me very much is that I have been looking at this audience and I see that our major speaker is completely deaf, and I am completely deaf, but there are only two deaf people in the audience. I think this is an attitudinal barrier. It is thought that if you are deaf you are not able to become a regular college student, at least not in a regular college situation, that you must go to a college for the deaf or a vocational school. I am very concerned about this because I know from my own experience that it is possible for a deaf person to obtain a higher education. But I know of only two other deaf women who have gone on to obtain a doctoral degree in science. I hope to encourage other deaf people. As Dr. Gavin mentioned, one must be qualified to obtain employment. One of the reasons I am participating in this series is to publicize that handicapped people, including deaf people, are not stupid. We can do much more than work in manual trades. Currently, I am working with the American Association for the Advancement of Science in their programs for the handicapped scientist. I am hoping to show what people with physical disabilities are capable of doing in science.

MS. FADDEN: Before I tell you why I am here I should tell you a little about what I do, because my company, Associated Merchandising Corporation (AMC), is not quite as well known as Con Edison. Basically, we are a buying office and a consulting firm for thirty retail stores. Bloomingdales and A&S might ring some bells for you; they are our two client stores in New York. I work with personnel executives in all of our stores, training them in various aspects of personnel administration, including hiring and the legal obligations of job interviewing. That is one of the reasons I am here—to learn from you and to pass some things on to you in the hope that you can learn from me. I have worked for a number of years in retailing and I know that there are a variety of jobs involved. Retailing has hired handicapped people in the

past and continues to do so. We have fewer physical barriers than many other types of companies. Since we encourage handicapped customers, it makes good sense to have handicapped employees as well.

MS. BACHMAN: I am the student member of this panel. My problem is slow reading. I can say openly that it is very, very hard for a student who is a "slow learner" to enter into any field of scientific study. Yet with tutoring there is no reason that I cannot learn any program of science. Occupational therapy and physical therapy and nursing are closed to people who have slow-learning problems. They say there is so much competition they cannot accept a student who reads slower than a "normal person." Con Edison has no timed tests; this is something that we need to work on for all licensing exams in order that the handicapped may be able to enter these fields of work when they have the ability to do it. The problem is mainly that slow learners are not seen as disabled. But we have difficulty in preparing for exams on time and in taking exams under normal conditions. So we are treated as inferior, and this is something that has to be addressed.

QUESTION: I would like to ask Ms. Fadden whether she thinks the public will accept a disabled person in retail sales, say on the floor of a department store.

MS. FADDEN: As in every other field, there are a lot of behind-the-scenes jobs in retailing—management positions, supervising of sales people, data processing, financial positions, personnel positions—that you do not normally see when you walk into the store. That is where the bulk of the employees are.

QUESTION: Do you have any jobs that entail being on the phone constantly—jobs you could do from your home a lot of the time without going into an office?

MS. FADDEN: The companies I work for do not generally have that kind of job. I know there are some retailers that do, but for the regular department store, employment is mostly in the store.

QUESTION: Do you get into fashion design at all?

MS. FADDEN: Yes, Associated Merchandising does. They have what they call market reps, who research what the fashion trends and colors are for the next year, and so on. It is an exciting kind of job.

QUESTION: What about communications?

MS: FADDEN: Yes. In the communications area we have advertising and sales promotion jobs.

MS. WARNER: I would like to come in on the tail end of that. One of the things I pointed out was the change that has occurred within Con Edison in the hiring of the disabled. I would like to tell you the story of a mistake we made that was very, very decisive for us. We work in many areas under Comprehensive Employment Training Act (CETA) funds for employing minority groups. We hired a group of fifteen meter readers and, in our ignorance of the company's regulations, put a man out into the field who had limited use of one of his arms. We thought he was great, he thought he was great, and everyone else thought he was great. One year after his being placed in the field he went into our medical department because of a respiratory problem. By this time he had won a special award because of his performance. The medical department told him that because of the limited use of his arm he could not be a meter reader. This was after one year of performing not well but superbly. He was placed in a clerical position—on equal pay. The man took us before the Human Rights Commission. And he won. Now not only is he back in the field, but our senior vice-president has given orders that by the end of the year every position in Con Edison has to be reevaluated as to its medical restrictions. One incident overturned what had been going on in the company for years.

QUESTION: In doing this reevaluation, where are you getting the input, how are you validating your judgments as to the medical restrictions tht should be placed on jobs?

MS. WARNER: There are two parts to this. We have been working for quite a few years with a management consultant firm. We started out working with them to change our testing system for weekly positions. (For management positions we have no testing system.) What they were able to do for entry-level positions was to devise a "career ladder" that would apply to jobs—an assessment as to the physical, motivational, emotional, intellectual, or whatever traits required by that job. This technique made it possible for us to be completely nondiscriminatory. It was a boon to the disabled. It was a boon to everybody. We cannot impose any restrictions other than those absolutely necessary for that career ladder. Now we are able to take those norms and start applying them to the medical restrictions. It was a gap that just had not been thought of before our meter reader won his case.

QUESTION: In 1968, when I started living here, I applied to Con Edison and New York Telephone Company, and they told me they could not hire me because my disability made it impossible to get proper insurance.

MS. WARNER: 1968 was before we had our incident. I would not be able to tell you whether or not you would still get the same answer for the position in question. We have to wait until the end of the year

before that is judged. Insurance has been a big problem to many employers in hiring the disabled. We have not found it a tremendous problem, and we can only cite our experiences—that to date our insurance has not been hurt, nor have our payments been raised considerably. But I know that many companies are petrified about that aspect.

DR. HOURIHAN: We had a discussion in class last week about this very issue. Some insurance companies are very reasonable; they understand the ability of the disabled to function without all of the dangers that the insurance companies see in the job. But, some handicapped, in order to get a job, have to waive their liability rights; the company would not have to pay insurance on them. And this becomes a problem. A great deal depends upon which company is insuring that corporation's employees.

QUESTION: I would like to add that in 1968 I was applying for the same type of work I had done before becoming disabled—it was designing work. There was no risk involved.

DR. HOURIHAN: The only way I could throw light on that would be by finding out which insurance company the corporation was dealing with, because different insurance companies have different standards. That is the problem. The disabled have to take this problem into account when seeking employment.

QUESTION: There is one perspective on this question that I would like to share. I was recently at a seminar where an insurance broker was speaking to precisely this issue. His comment was that if you stick with the big corporations, the larger companies, insurance usually is not a problem because—unless a firm employs a very high percentage of disabled people, a really significant percentage, disabled people are simply incorporated into the whole group. What does happen is that employers are not certain what the policies are concerning disabled people; they are ignorant of the policies or they have not encountered the situation before. According to this insurance broker, it is often the employer's ignorance on this point that constitutes the problem. Because if the company is large enough, it is not really much of a problem. But it is something that disabled people need to inform themselves about, because it is often raised as a problem.

QUESTION: How would you deal with a company that was worried about its insurance?

MS. WARNER: I think that one of the things you might do is point to the track record of companies that have had good experiences, that have not had any problems. Then try to get the company to

actually face their carriers and find out what the rules are. Because, as was mentioned earlier, the rules vary from carrier to carrier.

DR. HOURIHAN: Years ago the insurance companies used to assume that deaf people were very bad automobile drivers. Then they did some research and found out that the best safety records were among the deaf. Deaf people apparently are more cautious when they are driving a car, inasmuch as they are very conscious of the fact that they cannot hear automobile horns. Research has to be done in many areas, so that we can prove the facts—and not just to employers. Many times the employers want to employ the handicapped. But if the insurance company refuses to protect them, then it is the insurance companies we have to work on.*

QUESTION: I would like to know if pre-employment screening tests are adapted for people with handicaps, and also how training programs are adapted.

MS. FADDEN: I cannot respond for all retailers, only the thirty stores that are members of AMC. We encourage them to make adaptations for people with handicaps. Most of our stores no longer use aptitude or written tests. They use skill tests only: if you come in and you want a job that requires the use of a typewriter or a computer terminal, you will be tested on your skill in using that. So at least for the companies that I work for, testing is not an issue anymore. It still is in many places. Except for typing or some other specific skill, we have suggested that tests be eliminated because we cannot validate that they have anything to do with job performance. If a test has nothing much to do with the job, why use it? And the elimination of tests saves money. I think you will find that tests are less used in retailing than they used to be.

With regard to training programs, we realize that different types of adaptation are required depending upon the person's handicap. Most retailers today have extensive video equipment and audio equipment that can be used, and some have braille or other types of equipment. We have not had much difficulty making training adjustments. Sometimes getting past the interviewers is tough, but not the training.

*A clarification of the insurance issue as it affects the hiring of disabled employees appeared in the January-February 1979 issue of *In the Mainstream* (Volume 4, No. 1). The article states that, "... insurance costs do not release employers from the affirmative action and non-discrimination obligations of Sections 503 and 504 of the Rehabilitation Act. According to David Brigham, Handicapped Employment Specialist for the Department of Labor, insurance costs are not a legal reason for refusing to hire an otherwise handicapped individual."

MS. WARNER: I would say the same thing. We have not had much difficulty in adjusting and accommodating when it comes to the position guide, the job description. We have been able to get equipment that will enable people who are visually handicapped to function very well on the job. Not too long ago I interviewed three of our medical secretaries who are totally blind; one has been with Con Edison for thirty-eight years, one for twenty-four years, and one for eight years. There have been no problems; their secretarial work is done through a dictaphone. However, when it comes to some of the physical jobs, there could be a problem. We have people working on all sorts of high-tension power equipment (it is not only the individual's welfare but that of the entire city that is involved) and we are very careful. We cannot accommodate every job in Con Edison.

For management positions, disability is no barrier at all. There is no testing whatsoever for management positions. All the individual needs is the proper credentials. The credentials could be anything, depending upon what is needed for that job.

QUESTION: Medical secretarial jobs have traditionally been available to the blind. I would be more impressed if you mentioned some other position.

MS. WARNER: Give me a job that you would consider, and I will tell you if it is possible or has been done in Con Edison.

QUESTION: Programmer. A blind programmer.

MS. WARNER: No. Not that I am aware of.

QUESTION: There is also the problem of tokenism. The disabled are often given token positions in business or industry without a real effort to utilize their potential.

MS. WARNER: I can not speak for all industries; I can speak for Con Edison. One of the problems we have is that we are constantly in the public eye. But I can assure you that nobody stays around who is not doing his or her job, whether in management or in a weekly position. That may sound strange to you. You may often have seen a man leaning over a barricade, and he may seem to be doing nothing but standing by a barricade in the street. However—and it took me a long time to realize this—that man standing by himself looking down into the manhole is doing his job. He is the lifeline to the person down in the hole, working on live power. He is responsible for his fellow worker, for getting him out. And that is exactly what his job is—to look down into that hole and keep his eye on his fellow worker every minute.

Yes, tokenism could be a big problem. But we have come a long way in our hiring and training of all minorities—not just the disabled,

but women, blacks, Hispanics. We no longer employ them just because it is the nice thing to do. That was phase one that I mentioned earlier. That used to be Con Edison's policy. Now we are trying sincerely to focus on the ability and not on the disability. We are glad that disabled people are showing their resentment of what we in industry have begun to call "the telethon syndrome." But this paternalism is not all the fault of industry. I am so glad to see the people with cerebral palsy revolt against that image. Because what was it emphasizing? Not the ability of the person, but the disability of the person. It was letting corporations ease their guilt feelings by pledging money. Where was the social responsibility? Where was the responsibility to develop the individual, whether disabled or not? Once employers begin to say, "Hey, it's not enough just to ease our guilt feelings; we have to do something for that person," you get into phase three where the corporation looks at the individual, not the disability. Phase two was compulsory compliance: legislation is passed and a corporation has to comply. But we have gone further. We have done a great deal to integrate all minority people into the corporation. We do not have separate training programs; the disabled are right in the basic training program. I would like to ask Dr. Sharpless if she would like to comment on this, from her perspective of trying to integrate the disabled into the sciences.

DR. SHARPLESS: I am not quite sure what type of comment you would like me to make.

QUESTION: The question, basically, is how were the visually disabled to be placed in various positions? What accommodations had we in industry made? From your perspective, how do you see the visually disabled being integrated into science?

DR. SHARPLESS: In science, I believe that most of my problems are attitudinal—I am shunted into a more sheltered position, I am not pushed to compete. I do present my research in public, but I am not encouraged to do that. I am not encouraged to learn how to do grant writing or anything like that. I am more or less told that I am better in the laboratory, and somebody else should do the public relations sort of work. I believe that with encouragement I could do much more than I am presently doing.

QUESTION: There is a doctor in San Francisco who is badly hard of hearing, but uses a stethoscope.

MS. BACHMAN: He became a doctor only because of Temple University. I say openly, Temple is unique. Dr. Harman would have been accepted nowhere else. And may I tell you that he is doing his residency in psychiatry at the University of Pennsylvania, which, as far as I am concerned, is one of the best hospitals in the country.

DR. SHARPLESS: Deaf people do have problems getting into the medical profession as M.D.'s. I have known only two or three who have been able to gain acceptance into medical school. The barriers are that you supposedly cannot interview your patient, cannot take a blood pressure reading, cannot keep up with the fast pace of the course work. But I believe that you should be allowed to have the opportunity, and I am pleased that the Albert Einstein College of Medicine is very tolerant toward hiring the handicapped; at least one handicapped graduate of the school of medicine has been hired and another is applying. They now have electronic devices that take the place of the stethoscope. I also should point out that not all physicians use a stethoscope, and that many of them, once they get through their preliminary training, specialize. If you are not in general medicine, and you are not in, say, cardiology, you may have no need for a stethoscope. You would naturally choose that branch of medicine in which you were least disabled.

QUESTION: Something that Dr. Sharpless said about public relations and other work involving public contact sparked a question I would like to ask Ms. Fadden. I would like to know what would happen, and perhaps what you think ought to happen, if a disabled person walked into the room now who was clearly qualified to be a salesperson and to fill that job. What do you think would be your response to him and how do you see your role in that kind of situation?

MS. FADDEN: I am not a representative of Bloomingdale's, so I can only tell you what my ideal would be. Handicapped people with different types of disabilities are going to encounter interpersonal problems of resistance and discrimination—not only with other employees but also with customers in a sales situation. If you and I could sit down in an interview and discuss this problem, and if you could show me that it was something you could handle, then I would give you the job.

I would like to add that retail department stores are not federal contractors, which means they are not covered under the Rehabilitation Act. This situation puts an extra burden on the interviewee to say, "Hey, I really can do this job"; because, as a disabled person, you do not have legal recourse under the federal law. There are laws in New York State that cover some aspects of discrimination on the part of nonrecipients of federal funds; but there are no such federal laws.

QUESTION: That is an interesting answer, and it goes back to the question that struck me when Ms. Warner was talking about evaluating jobs. Who decides what is possible for a disabled person to do? Who decides what is possible for the blind—or the deaf, or whomever—what kinds of jobs are possible? Ms. Warner mentioned danger and that Con Edison would not want, for example, to put blind people in situations

that are potentially dangerous. But I know a number of "hams"—people who are qualified as radio engineers—who happen to be blind. They have had enormous problems gettting jobs with radio stations or whatever, because the employers are convinced that employing a blind person would be too dangerous. But these people know how they intend to cope with dangers. They know what the dangers are. You were speaking earlier about job evaluation; I wonder if you solicit input from your veteran disabled employees in terms of just what is possible, what the concept of "danger" ought to be, what the real limitations are.

MS. WARNER: Yes, we do. In fact a great deal of the modification of job limitations has come from the input of these employees. When I say "dangerous," I mean actually out in the field—the manhole type of situation or working in a plant where there are dangers. Working on technical instruments would not be a problem. A person could function very well there. We do consult with the people who have worked in these various areas. But one thing we are trying to avoid is what we call "the next person through the door" syndrome, which means this: if we have a receptionist in a wheelchair we do not want management people to say, "This person in a wheelchair is a wonderful receptionist; let's make the next one a receptionist," and so on. We are trying to get away from that kind of stereotyping. We want to focus on the jobs themselves and on the individuals themselves. And yes, we do take a great deal of input from our people.

QUESTION: I would like to ask the two representatives of industry whether they have really abandoned testing.

MS. FADDEN: Except for work samples, our tests are almost entirely for the testing of actual proficiency and skills.

MS. WARNER: We have not abandoned testing, but we have changed it to something called threshold traits analysis. When we take a person in at entry level, we do not want him or her to stay there. The key job in every career ladder has been analyzed, and we have to determine whether that person can reach the key job and keep the employment stream flowing. So every career ladder has its own test.

QUESTION: Could you give an example of such a test?

MS. WARNER: Yes. Customer service is a job ladder. The meter reader is at the bottom of the customer service area, which goes up to the customer service representative, senior customer service representative, eventually up to supervisor. The middle point, the customer service representative (CSR) is the key point. There is a battery of tests. The first is a test which demonstrates how you would record addresses.

A form is given. The company abbreviations are used. Can you duplicate, over a series of addresses, the exact form? The second test involves an illustration of meters. The basic instruction is given as to how you would record a meter reading. Can you follow the instructions? Can you look at the simulated meters and write down the numbers as they would be given? Another part of the CSR test, the third part, is basic computation—addition, multiplication and division. In addition to these tests an interview is given. The interviewers have been instructed in this whole method. They cannot ask you anything that is not needed for the particular job for which you are applying. The interview and the tests go together. The employment of the individual is based on that.

QUESTION: What kind of feedback do you get from nondisabled employees about the disabled?

MS. WARNER: We have had so much experience—not only in the hiring of the disabled but in the retraining and replacement in other positions of people who have become disabled on the job—that integrating them into our work force is not the big difficulty. We did find concern among supervisors for the safety of the disabled, as to what would happen if there were an emergency. Because our buildings are old. Also—and I hate to say this, it sounds terrible, as if we are always fraught with emergency—we get so many bomb scares in Con Edison. Most of them are not real, but we live with bomb scares. We have worked with New York University Medical Center and have adopted their evacuation procedure. For each of our disabled employees, we have assigned one person as an immediate escort, with a second, backup person in case the first person is not there. Wherever possible, the disabled employees' work locations are within fifty feet of an exit. We are no longer as nervous about it as we used to be. We have done a great deal to calm management as well as the disabled employees, and it has worked very well.

MS. FADDEN: Coming through the personnel office when I was working in the stores, I used to get the same sort of comments about the disabled as about anybody else: somebody would come in and say, "Oh, I'm going to kill so-and-so!" or "Get so-and-so out!" or "Gee, he really did a good job." I think integration of the disabled is more a matter of overcoming management fear than anything else. From what I see going on every day, once the initial getting-to-know stage is over, there is no difference.

MS. BACHMAN: In other words, we are human beings first and only second do we have a handicap. It is very important that we see ourselves first as individuals of value and then accept the fact that we have a handicap. I think that one of the biggest problems—and this is

something I studied when I was at Pace—is the fact that most people see us as handicapped. We absorb this outer image of being inferior, instead of realizing that the handicap is only a small part of us, that we have a large part of us that is talented and capable of doing things.

I think this type of meeting and this type of discussion and getting together will help break down the barriers. At least I hope so.

MS. WARNER: May I add something to that? The whole discussion seems now to have gone over to attitudes. We spent one entire summer working with handicapped people at Rusk Institute. Our entire office staff of twenty people were going down there, more to gain increased awareness than anything else—to discuss how the handicapped see their problems in employment, how they see our role and their role in industry, and so forth. By the end of the summer, we found our attitudes had changed. We were relieved to find out that they were normal people; they did not think they had to be stronger than anybody else; they knew that there would be times on the job when they would not want to do it; they knew that sometimes they would be late, that sometimes they would be absent, that sometimes they would hate the supervisor. Once they admitted all this to us, suddenly we were all people together. We at Con Edison were unprepared to work with saints, we were prepared to work with normal, everyday, accomplishing, striving people. And when we got it adjusted in our heads that that is what handicapped people are, the stereotypes broke down. They were realistic about themselves; we could be realistic about them.

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The Provision of Social Services: A Dilemma for Our Times

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The last time I stood on this podium was about two years ago. Then, I was delivering the address for the Martin Luther King commemoration. I think that this gathering today is altogether fitting as a return engagement because Dr. King was, for many of us, the charismatic leader who set in motion the forces that have brought us all together, enabling us to talk openly about the rights of minorities, of women, and of the handicapped.

I was a delegate-at-large at the White House Conference on Handicapped Individuals. Let me tell you how I came to be there. I have been using crutches for about four years. I was handicapped as a child but had no need of a walking aid. However, as I have grown older my disability has worsened, and as many of you can well understand, I have had problems adjusting psychologically to that. Because I was continuing to pursue my career in spite of becoming increasingly disabled, my friends felt that I should begin to act as a spokesman for people with similar difficulties. As a consequence, I was asked to speak at an Urban League conference on the minority handicapped. My speech was very well received; excerpts were published in *The New York Times*, and when I arrived in Washington as a delegate-at-large I suddenly found myself a celebrity. I was asked to speak at yet another meeting and ended up organizing a caucus on the non-white handicapped. We were very successful in that effort. If any of you have had a chance to read the final report of the White House conference, you will find that the Report of the Non-White Caucus on the Handicapped is included in its entirety as part of that document. One of our demands had been the inclusion of the full caucus report in the conference's final report.

Looking back over my life I can say that I have been lucky in many ways: I have had the support of a loving family; I have had the capability and interest to become educated and to pursue a career, even as my condition worsened. One fact amazes me today—that being handicapped is news. Years ago it was not. This alone suggests how much times have changed. Every day in the news media you will see

a feature about a handicapped person who has made it, or a news item about the gains being made by the handicapped in employment, in education, in removing barriers to self-sufficiency. Such gains, I must say, have been achieved primarily through the tremendous efforts, both political and legal, of handicapped people themselves.

This is a far cry from the situation that prevailed years ago, when we, the handicapped, hid from public view and felt too ashamed and ill-equipped to compete for jobs or fight for our own interests. Times have changed. But I caution you, they have not changed as much as we would like. Being handicapped may be news; but for far too many handicapped people and their families, being handicapped still constitutes a tragedy, still condemns many children and adults to be closeted in the apartments and tenements of such neighborhoods as this one on New York's West Side. If economic, educational, and job resources and benefits were more easily accessible, they could do much to alleviate the poverty, the dependency, and the dehumanizing conditions we have come to associate with the poor and disabled among us. But such benefits, and ready access to them, are shockingly lacking.

Because of the concern about this situation, the planners of this Distinguished Lecturer Series asked me to address the topic of social services—a field in which I have been employed as a professional in one capacity or another, paid or volunteer, for twenty years. I was originally asked to speak about employment opportunities in social services. But I felt that in keeping with my own interest (and I hope yours), I might talk about the field of social service in general and share with you some of my thoughts about social service for the handicapped—and indeed for all of us. As a consequence of my life experiences and professional training, and because of the many programs with which I have been involved over the years, I believe that I am well qualified to speak to you about social service—my life's work. As a professional in the field, I hope that I can excite you—especially those of you who are concerned about a professional career—to look upon social service as fertile ground.

Now, about me. I have a master's degree in social services from Bryn Mawr College, which I received in 1962. My concentration was in social work research. I began work in the public sector as a field caseworker, and later served as director of a large city agency responsible for children's services. When I was appointed to head New York City's Agency for Child Development (ACD) as its first commissioner, I was interviewed by *The New York Times*. At the time I was using a cane, and in his news story the *Times* reporter quoted a statement I had made at the time I was being interviewed for the job: that I am black, I am a woman, and I am handicapped. Out of these three facets of my life has sprung the kind of concern I have about handicapped people and about people generally.

Prior to joining ACD I worked in private voluntary organizations, in community psychiatry, in a settlement house with pregnant

teenagers, and as a policy researcher—the last being the most closely related to my area of specialization. My most recent appointment is as deputy general director of programs for the Community Service Society (CSS).

With over 300 employees, CSS is one of the most prestigious social agencies in this country. We engage in social policy analysis; we do legislative advocacy; we provide direct services for the aged, for handicapped, for youth. We also provide technical assistance to community boards and to school boards. At present we have a very interesting project on New York City's West Side called the Education Direction Service. The project is being funded by the Bureau of the Educationally Handicapped to provide an advocacy service for the families of children who should be receiving education through the public system. Our staff is knocking on doors in local housing developments and apartment buildings, trying to locate handicapped children, trying to inform parents of their children's right to education, and trying to provide the services that will ensure that right. This project has been in operation for only three months, yet we have already located over one hundred children locked in the apartments of Manhattan's West Side, children who are not receiving education because their parents are either unable to get them to school or unaware of the child's right to public education. Many of these parents are so burdened by poverty—and in many cases additionally overwhelmed by their inability to speak English—that they are quite unable to deal with the needs of a handicapped child.

The provision of social services in the United States has undergone quite an upheaval since my graduation from college fifteen years ago. This upheaval has been twofold; in the recognition of public responsibility to alleviate a variety of social and economic disadvantages, and in the perception of what constitutes human need. I can recall that twenty years ago it was by no means *de rigeur* to talk about the rights and needs of the handicapped or the rights and needs of the poor, much less to entertain ideas about individualized education or any of the various approaches to the provision of services that have emerged and become widely accepted in these few short years. And although we have never felt comfortable in this country with the notion of universal social and economic benefits that would ensure a minimum standard of living for all, we have moved grudgingly toward the acknowledgement of public responsibility for certain aspects of human development, such as education and health services. We have accepted the proposition that the handicapped, as well as women, non-white ethnic minorities, and other disadvantaged groups, have a right to education, employment opportunities, and self-respect. But we have yet to create the resources and the accountability mechanisms whereby these rights may be ensured.

The economic and social plight of children, low-income families, and disadvantaged individuals has preoccupied public policymakers

over the past fifteen years, as witnessed by the spate of governmental activity at the federal and local levels. But disagreement about the most viable means of improving the lot of the poor and disadvantaged has predominated. For instance, should assistance take the form of services through such programs at Title I, the Elementary and Secondary Education Act (ESEA), Head Start, or day care–all of which may be substitutes for cash? Or should government concentrate its efforts on increasing the cash resources directly available to the poor and otherwise disadvantaged, thus enabling them to purchase services in the market for themselves?

Each position has its adherents and reflects a certain bias of approach to the disadvantaged as well as a difference in the way that disadvantage is perceived. The result of the failure to reconcile these positions is a disarray of policies and programs at the governmental level. One has only to look at the slow pace of implementation of PL 94-142 to appreciate the problem.

Let us return for a moment to the Education Direction Service operated by CSS on the West Side. The law mandates that education shall be available to all. Yet there is little chance that a handicapped child will get into the school system unless someone intervenes to make such entry possible. Moreover, the level of income a family needs to be able to maintain a handicapped child in school has to be part of the service package. Who puts the package together? CSS has to. There is no coordinative public policy.

Then there is the problem of jobs. Government has scarcely recognized the need for the mass deployment of funds to produce jobs and concrete job resources. A number of politicians do stress jobs as a solution to many of our economic and social ills; but they do so, I believe, from the perspective of reducing public assistance costs. Scant thought is given to improving the labor marketability of the handicapped, of women, of the unskilled poor. If you take a look at our public assistance programs, for instance, they operate in such a way as to continue the poverty and dependency of the handicapped and the poor. If you are handicapped but have the capacity to work, little support is available to make that capacity marketable. And if you do succeed in getting and holding a job, you must then run the gamut of eligibility requirements–for Medicaid, for transportation assistance, for all the services you need to make it possible for you to go to work every day. Nothing in our system mandates tht the right to employment or the right to education carry with them the right to the means to purchase the services that would make such rights viable.

Now you may well ask, "What does all this have to do with social services?" I submit that these issues are the threads of which our social services dilemma have been woven. Until fairly recently, social services were primarily viewed as help to be given when individuals and families could no longer care for themselves. This view, based upon English common law precepts, served to limit the nature and extent of social

service provision. To cite one example, public responsibility for the welfare of children was acknowledged only at the point of family breakdown. And then the solution was (still is, I might add) to place the child away from home. The result of this policy has been the evolution in the United States of a child welfare system, usually operated by voluntary, sectarian-based agencies, whose major emphasis is upon placement. These agencies nationally serve over 300,000 children, a disproportionate number of whom are handicapped. Because of the tendency of any organization to reinforce its existing institutional arrangements, the child welfare agencies have been slow to develop the types of services that would shorten the separation of children from their natural parents, and the public sector has been reluctant to prod the agencies into doing so—either through financial incentives or by monitoring agency care of children. This issue is so controversial that it has given rise to an endless stream of studies, court cases, and legislative challenges over the years. Yet the child welfare system remains essentially unchanged. Many children are placed because parents are unable to cope financially or emotionally with their care—which would seem to suggest that the need for preventive services is paramount. Yet the agencies tend to react only after the fact of breakdown.

The provision of child welfare and of care for the mentally ill, the disabled, and the indigent poor has been the responsibility of state government over the years; but the services provided have been remedial rather than preventive. Until recently, public aid for poor and indigent people was rarely available, and then usually in less than humane circumstances. We need only consider Willowbrook and the fight to obtain the Willowbrook consent decree to realize that the point I am making is still an issue of public policy.

I would like you to reflect for a moment, if you will: Some of you can personally recall the Depression of the 1930s, when some of the issues I am raising were even more controversial than they are now, because there was then no federal involvement in the provision of social services. The crisis of the Depression created a public demand for the federal government to assume a direct role in this area, resulting in passage of the Social Security Act of 1935. This legislation represented a long struggle between government and social reformers about the extent to which government should assume responsibility for economically deprived children and aged adults. The Social Security Act, modest in the numbers of persons it initially entitled to benefits, is now far-reaching in its approach to social and economic distress. It not only provides old age insurance but also has been amended to provide disability insurance, Medicaid, and Medicare. More recent amendments have added funds for child welfare and for such additional social services as foster care, day care, and homemaker and housekeeper services.

Until the 1960s the Social Security Act was by far our most

important piece of social legislation. With the advent of the civil rights movement, augmented by the demands of professionals working in the field of human services for an increased federal role in the provision of aid to children and youth, an avalanche of social legislation was produced whose impact is still being debated. However, if you consider all that has happened in the last fifteen years—and I use fifteen years as a yardstick because it coincides with the span of my own involvement in the administration of these programs—you will find that we ended the sixties with a retreat from the kinds of social concerns reflected in the Economic Opportunity Act, the Elementary and Secondary Education Act, the Model Cities Program, and many other legislative programs.

Nevertheless, I would like to point out that while many of us may be cynical about what has taken place during the 1970s—resulting in the diminution of resources and funds to help the poor and disadvantaged—some milestones about which we should feel proud have been attained. Certainly, the definitive declaration at the federal level of the right of the handicapped child to education has been a significant achievement. Much of the impetus for this kind of legislation has grown out of the Head Start program, out of Title I of ESEA, and out of advocacy by and on behalf of the handicapped for this kind of definition of individual rights and governmental responsibility to ensure these rights.

Many social policy experts, moving now beyond the provision of services or the articulation of rights, are recommending the provision of family allowances and a guaranteed minimum income as the most effective way of dealing with such matters as the inequitable distribution of income. Such proposals are not new; they have been presented at intervals over the years; but the political resistance to such a shift in public policy has been intense. This society is imbued with the belief that individuals function best with the least governmental interference. In general this may be true; but such a belief ignores the need to correct existing social inequities among individuals and among families—inequities that are readily apparent when we consider the poor, the handicapped, and the disenfranchised among us.

Out of these concerns, then, comes my commitment to social services. For this is one of the few fields in which an individual can wed his political-moral philosophy—based upon human rights imperatives—to the use of intellectual and technical skills, in the pursuit of social good. Social services can be broadly defined to include needed services that cannot, for whatever reason, be provided without public or community support. Such needs include health, education, and recreation, as well as a range of such personal needs as homemaker services for the elderly and the disabled, and day care. The key element in assessing the need for the public provision of social services is the inability of the individual or family to finance or arrange for them unaided.

The single largest provider of social services is government. At the national level we annually spend $5.1 billion for education, $3.4 billion for health, and $2.5 billion for social services excluding income assistance. When one includes outlays at the state and local levels, particularly for education and health, the public costs rise sharply. In New York City, for example, the annual expenditure for health is $1.6 billion, and for education it is $2.9 billion. It follows, then, that government is also the single largest employer of social service personnel. Since social service expenditures are primarily for personnel, you can imagine the multidude of jobs created by the outlay of these billions of dollars.

Numerous professions are involved in the delivery of social services—physicians, psychologists, psychiatrists, nurses, lawyers, teachers, rehabilitation counselors, and of course, social workers. Since I am a graduate social worker, I will limit my remarks to the training needed for that profession. To qualify as a social worker, one requires a master's degree from an accredited school. During graduate training a student may concentrate on casework, group work, or community organization. Some schools of social work are now expanding their curricula to include social policy and research, particularly at the postgraduate level. And some are providing joint courses with schools of law, public health, an education.

A small number of social workers are engaging in private clinical practice. But the great majority are to be found in state and local departments of social services—working in health and mental hygiene, in child care, or in the provision of services to the disabled and the elderly. Finally, a few, I among them, are engaged in policy analysis and research.

The social services system—like its flagship profession, social work—is at the crossroads, confronted with the dilemma of whether to move in the direction of universality of coverage and benefits or become even more specialized and targeted to meet the needs of particular groups of disadvantaged persons. Similarly, the social work profession has to grapple with the issue of whether to develop generalist practice, designed to underpin a universal social service system, or whether to enhance specific skills—in clinical practice, in community organization, and in other specialized areas.

It is my firm belief that the social services, and social work, must embrace the notion of universality, because families and individuals are finding it increasingly difficult to survive unaided in our modern techonolgical society. With that in mind, we need to remain flexible in the way we perceive professional practice and training, and not adhere rigidly to modes of behavior that may render us incapable of responding to the needs of an ever-changing society. This approach is, I beleive, in keeping with my professional heritage and my commitment to social change.

PANEL DISCUSSION

Panelists: Tom Clancy, New York University
John Deely, Institute for the Crippled and Disabled
Research and Rehabilitation Center
Jim Diffley, Abilities, Inc.
Rosalind Rubin, New York State Department of Labor
Janet Severt, Ramapo College

MR. CLANCY: Ms. McMurray mentioned a number of things that I would like to follow up on a little. One of the problems about the disabled in the city of New York is that we do not even know how many there are. And there seems to be no way to find out. We do not even know how many disabled people have applied for assistance. And there seems to be no way of finding that out, either. In fact, it seems to be difficult to find out who is in charge of what.

One of the problems with employment is that as a severely disabled person it is almost impossible to pay one's own way. You envision, when you begin, that a $20,000 a year salary will enable you to live a nice comfortable life. Well, I make that, but it does not work out. I am now in the process of trying to get Medicaid assistance to enable me to keep working—which seems absurd. The problem is that the definition of disability is based on economic capability, not physical capability. But apparently things are changing. Among the changes is an effort by the city of New York to define catastrophic disability. This would remove the catastrophically disabled from a purely economic definition of their disability and perhaps make employment more feasible. The new federal regulations are good, though I would say fifty years overdue. But they do not promise anything. Government is sitting out there waiting for us to make our move. The disabled community is probably the most silent minority that ever existed. One of the reasons the Washington conference was so beautiful was because it was the first time, I think, that the coordinated voice was heard. It was an exception to the rule.

I do not believe that you can work unaided if you are severely disabled. No matter where you may be with regard to education or anything else, you need some sort of assistance. In many cases the help needed is economic; in other cases it is psychological. But there is no way of doing it on your own.

Sometimes the problem is one of overeducation. I had been through Fordham's school of business and St. John's law school before I was ever disabled. Yet I spent sixteen years in a hospital. We seem to accept a person with a master's degree or a doctorate doing a clerk's job just because he or she is disabled. But some day that will have to change.

Another problem is categorization. Data processing is now a popular work category for the disabled. Why? Because some people have succeeded at it. Imagination—and I think this goes all the way to

vocational rehabilitation at the state level—is lacking. There is too much emphasis on success. Why should you not go for a doctorate in anthropology, say, even if the best job that industry will offer you is a clerkship? Why deny to the disabled the enjoyment of ecucation? Why categorize education for the disabled? As things stand, one is allowed to pursue only certain areas, for the most part, otherwise one forfeits assistance. I grant that there should be some connection between education, rehabilitation, and employment. But the mix should be much better than it is today. Another thing, it should not be assumed that everyone can benefit from going to college. There are people needing a job who simply are not college educable.

Then there is the problem of lack of follow-up. For the most part, people who obtain jobs and go to work are dropped from the system. Vocational rehabilitation says, "Okay, now you have a job, you're on your own." There is no consistent follow-up on what happens after that.

When I was in Goldwater Hospital, CSS was the first group I can remember that came in and treated us like people and got us involved in what you might call outside life. We were taught to handle finances, we were taught to project a future for ourselves. So CSS is an old friend.

There are great differences among the disabled. Consider the reflective individual, the person who is essentially a thinker. Such a person when faced with the loss of his or her physical capabilities turns toward a mentally oriented job much more quickly than the person whose whole being was physically oriented—the once strong man, the once beautiful woman. There are complex problems here, and I do not think the system adjusts to them very well. There is something beyond employment. There is the element of pleasure in life. When you are disabled, the amount of pleasure remaining in life becomes more and more limited. If your employment scope is also severely limited, then what is left in life for you?

Finally, I think that we are today on the verge of a new era. I believe that the disabled community—especially the employed disabled, though a very small minority—has something to offer. I know that when I finally went to work I gave something more to my office than my office gave to me. But it took me a long time to realize this. I think that perhaps the greatest impetus toward employemnt of the disabled would be to make employers aware that we have something more than skills to offer. We have an attitude toward life that brings something extra to the job.

MR. DEELY: When I went to work at the Institute for the Crippled and Disabled Research and Rehabilitation Center (ICD) as a job developer about five years ago, I felt that I was drifting outside the pale of social work; because rehabilitation was an area rarely mentioned in the school of social work. As a matter of fact I, with a master's degree

in social work, knew absolutely nothing about the field of rehabilitation. That tells us something about where social work is in terms of its involvement in helping handicapped college students prepare for employment that is both financially and psychologically rewarding. However, I believe I have learned a few things along the way and I think any good social worker can do the same. I am overjoyed to see that as a result of Section 504 more and more handicapped college students are mixing with the nondisabled population.

When I was in graduate school President Nixon had more or less declared a truce on the war on poverty. But there was still a certain amount of leftover verbalization about "interest in the poor." One of the maxims we used to hear tossed around in the halls of Fordham's school of social work was that "programs for the poor are usually poor programs." The same thing, by extension, can be said about educational programs for the disabled that are not intimately linked, wherever possible, to educational programs for the population at large. Of course, many types of social and supportive services will be needed to achieve educational integration.

With regard to employment, the social work profession is first of all going to have to modify itself. It is going to have to realize that it can function in a manpower setting. A revealing article published about three years ago in a social work journal made the point that there is a role for the social worker in manpower fields. Social work as a profession has tended to feel that becoming involved in manpower operations would mean getting its hands a bit too dirty. I hope all that is about to change. If social workers are to be involved in counseling and in providing other services, they have to have a perspective on the world of employment. I admit to you quite freely that I did not have such a perspective when I graduated as a social worker in 1973. I hope I am on the way to becoming more knowledgeable about the realities and needs of the world of work, where the disabled and the nondisabled compete for jobs.

One of the dilemmas we at ICD frequently encounter is that people receive all kinds of services from the state agency and from other agencies up to the point where they are gainfully employed. Then, after two months, the agency that has been supporting them suddenly withdraws, and they are left with, for example, a fantastic transportation bill. Many handicapped college graduates cannot afford to work, because if they take a job they lose the sponsorship of the agency that helped them through college and they can then no longer obtain free transportation. As you are well aware, the cost of private transportation for a disabled person to get to and from work is at least $100 per week. Entry-level salaries get gobbled up just in transportation costs. Somehow or other these special services must be made available beyond the protected milieu of college. Transportation services should be available on a continuing basis to anybody who needs them. What we need is subsidized private transportation. At the very least, the

disabled person's cost of private transportation should be tax deductable. Business is allowed to write off the three-martini lunch as a business expense. Yet a handicapped person cannot deduct a single penny of transportation costs to and from work. That is a direction we could move in. Perhaps this problem also points up some hard decisions we have to make. Those of us who are counseling college students have a responsibility, before advising them to get into a certain field, to find out whether or not that field's salaries will support them later on—unless you are anticipating, three or four years down the road, that the government will underwrite their transportation bill. If you fail to do that, the end result may be a college graduate who sits at home and develops a justifiable sense of bitterness against an establishment and a whole set of networks that promised a great deal and came through with nothing.

I also hope that colleges and counselors resist any attempt to coddle the handicapped. This may sound cruel, but the handicapped know they have to compete in terms of job requirements. They have to compete with persons who are not disabled, so it makes no sense to make things so easy for them that when they get out in the real world they are simply overwhelmed by having to live up to the demands. We, as advocates, have to make sure that handicapped job seekers get a fair hearing; but we should not delude them into thinking that they are going to have an easy time, that they do not have to compete on an equal footing with their nondisabled co-workers.

Finally, I would like to offer a career guidance tip to handicapped students working toward a college degree. If you want your bachelor's degree to serve as your entree into the world of work, a lot of preliminary research needs to be done before choosing your major field of study. One of our main probelms at ICD is that many handicapped students come to us with what I would call a nonmarketable college major. One girl came with a degree in black studies; I asked her what connection she thought this kind of major had with getting a job, and she said simply, "I don't know."

Now this may be an unfortunate thing to have to say, but like Avis, the handicapped have to work harder. As we know, people who are not disabled can waltz through college and then somehow land on their feet afterward. If they come out of college as psychology or history majors, they can usually make some type of lateral shift and obtain a fairly rewarding job. But the options available to the handicapped person are much more limited. Therefore it behoves all of us who are involved in career counseling of the handicapped to help them make wise decisions. We need to carry out careful, in-depth research of a student's proposed field—its requirements, its demands, the sort of possibilities it will be likely to offer four years later, when the student is graduating.

MR. DIFFLEY: It has been mentioned that employment often is not

practical from a financial point of view. And I think we have found even in other ways it is not always practical. One of the biggest problems for disabled prople is that they need help in meeting certain disability-related expenses. For instance, one of my colleagues, who is quadriplegic, needs to use a gel pad to prevent sores developing while he is seated for long hours at his work. I was quite surprised to learn that he has to replace the pad fairly frequently and it costs $300. That is really a great deal of money—certainly more than he makes in a week—and it has to come out of his own pocket. Tom Clancy mentioned that even with a salary of $20,000 he is not able to manage. It would, I think, be very helpful if ways could be found to supplement people's incomes once they are employed. After sixty days of employment, the Office of Vocational Rehabilitation (OVR) closes the case and one is on one's own—not only for transportation but also for any other unusual expenses. This fact sometimes makes people reluctant to render themselves ineligible for benefits—whether social security disability insurance or public assistance—by taking a job. As Ms. McMurray mentioned, it tends to create a certain degree of dependency. These disincentives render some people unable to work no matter how much they may want to.

About education, I have found that the people who do go in for higher education—a bachelor's or master's degree—do not always wind up as clerks. Maybe the people I know have been more fortunate than those Tom is in contact with. What does often happen is that disabled people are underemployed. A disabled person may have a bachelor's or a master's degree and yet be hired at a lower salary than a nondisabled person with the same credentials, and the same types of skills, because the employer is somehow thought to be doing the disabled person a favor. So, apart from the problem of unemployment, which is quite high, there is also the problem of underemployment.

The social service system seems to be a bureaucratic mess. And probably those within the system are quite aware of this. But I have found that with proper persistence, perserverence, and enthusiasm you can get to the right people and they can be very helpful. But you have to plug away at it. One phone call, one letter, one visit may not be enough. Some people—the staff at the Human Resources Center (HRC), for example—project a great deal of enthusiasm and encouragement and an optimistic outlook; when one is able to contact the right people, be it Ros Rubin of the New York State Department of Labor or someone connected with Comprehensive Employment and Training Act (CETA) or Manpower, such people can be very helpful. But it is difficult sometimes to find them. I wish that everything could be found in one building or at one phone number. Maybe that is asking rather too much. Yet I believe services will in time become more centralized, and I think that if well managed, centralization would be a step in the right direction.

MS. RUBIN: Although I have been introduced as being from the New York State Department of Labor, I am presently on loan to the Civil Service Department. So, while I still represent the state of New York, I am currently coordinator for the metropolitan area of the governor's program to hire the handicapped. I worked for many years as a rehabilitation counselor, placing the handicapped. I returned to placement work this past year and found many changes (not enough, really) in the attitude of people who do the hiring. Even in state agencies, the preconceived notions of what a handicapped person is, and what he or she can do, are barriers we constantly come up against, and are constantly trying to knock down. As HRC and ICD know, I would never place a clerk in a professional job. The emphasis for everybody, whether handicapped or not, is on skills and qualifications for the job they are seeking. It is a very cutthroat, dog-eat-dog kind of world out there, even in state government. But we are mandated. The governor has said that 100 handicapped people in the New York metropolitan area and 100 in the rest of the state will be hired in state government.

People in state government do not come to me with jobs. I have to go after these jobs. I have to knock on doors. When I run into people in the hallways, I am forever asking, "Do you have a job for such and such?" That is the kind of labor market it is. All the various answers that you get in private industry you also get in state government; and I am sure that if the people who do placement work in the federal government and in city government were here they would have the same story to tell.

One of the things I am most concerned about and which has already been mentioned is the transportation problem for the working handicapped. I have no idea how people get my name, but they do, they find me. And because I am a rehabilitation counselor they sometimes think I am a social worker and a resource person for every kind of problem that exists. Recently I had a call from somebody who uses a wheel chair and spends $100 a week for transportation. The problem is that she needs a wheelchair, but as a single individual earning $12,000 a year she cannot get help. Frankly, I could not tell her where to turn for help. She said she had already called twenty people, and I believe her. Yes, I do think we should have a coordination of efforts. I think that we should be more accessible. I think that people who are in the field should be accessible to everybody, and that we should be readily available to answer your questions, to help.

The program I coordinate, 55B, is fairly successful. I hope that it is not going to be a temporary program. I hope that instead of there being just the fixed number of 200 jobs there will always be at least 200 entry jobs at the state level reserved for the handicapped. We not only place people, we also provide special help for anybody who needs it in testing. If you are going to take a civil service examination and you need somebody to interpret for you or you need a reader or you need a writer—that has also become part of my job. And I am at your

service for any information you may want, as well as for placement. As far as skills go, most of the placements I make are of a professional nature. Employers sometimes come to me to fill their affirmative action needs. They say they want a woman, or a black woman or whatever, and I try to fill such needs if they are reasonable. I will continue to do my best to place all of the handicapped who require my services.

MS. SEVERT: I am a college student, in my sophomore year, and I want to comment on what some of the other panelists have said with regard to the problems of the handicapped. I have had my share of problems with such things as getting help with transportation costs. For example, I need a second set of hand controls for my wheelchair, but since the Division of Vocational Rehabilitation (DVR) has already paid for one set, they are unable to give me $100 for a second set.

The other comment I want to make is that it is very encouraging, the goals people are setting and the help we are getting. One of the difficulties I experienced in the past was finding career counseling. I looked for years, all through high school, trying to find somebody who could give me some ideas as to what kind of job I could go into, what fields were open, what college to apply to, what to do when I got there. I went to DVR and asked for a list of wheelchair-accessible colleges. They had no such list; they could not advise me. They had the name of perhaps one such college. I had to search on my own. Libraries did not have the information. Nowhere could I find a compilation of the information I needed. And there were other problems. First I was told to go to such-and-such college. Then I was told to consult a psychologist to see if I was capable of attending college. At first DVR told me they do not pay college expenses. Then, a month before classes were due to start, they said, "Well, we can pay if the cost does not exceed x number of dollars." But if you want to go to summer school, they will not pay for that. We need some cooperation. A little more feeling for individual problems.

But I am happy with all that is going on—the goals people are working toward and all of the help we are getting.

Part Five

Recreation and Leisure

Mariann Soulek is the First Vice-President of the Nevada Association of the Physically Handicapped. She has been an educator, recreation leader and wheelchair athlete.

Athletics

Mariann Soulek

City of Las Vegas, Nevada

I have a wealth of information to share with you. My main topic will be organized wheelchair sports; but in addition to that I want to talk about mainstreaming in sports; accessibility of parks and recreation areas; the importance of physical activity–I really want to discuss that, it is one of my pets; and a wheelchair sports center–a little dream of mine. Also, I have brought along information about a number of resources that I would like to share with you and, which I hope will be of some value.

Probably the first time you heard about the organization of wheelchair sports was after World War II. Before the war there was not much going on in this area. The lives of people with spinal cord injuries were usually cut short by the onset of kidney infections. Shortly after World War II, antibiotics came into the picture, and these people were able to look forward to a much longer life. In fact they were able to live, in most cases, quite successful lives.

Three individuals who have been mainly instrumental in getting organized wheelchair sports going are Tim Nugent, who is at the University of Illinois and started the National Wheelchair Basketball Association; Sir Ludwig Guttman, an English neurosurgeon, who started the International Stoke-Mandeville Games; and Ben Lipton, director of the Bulova School of Watchmaking, who hails from across the river in Woodside, New York, and was instrumental in organizing the National Wheelchair Athletic Association.

The first organized wheelchair sports effort in the United States occurred in 1948, when the Veterans Administration hospital in San Fernando Valley, California, sent a wheelchair basketball team around the country playing exhibition games. A year later, the first national wheelchair basketball tournament was held at the University of Illinois under the direction of Tim Nugent. There were only about eight or ten teams that year. Today, there are over eighteen conferences and over a hundred teams competing from every part of the country.

In wheelchair basketball, each individual who competes on a team is classified: Class I, paralyzed from the cervical vertebra down to the ninth thoracic vertebra; Class II, paralyzed from the tenth thoracic

through the second lumbar; Class III, paralyzed from the third lumbar and below. To give you an idea, Class I individuals have no use or only minimal use of stomach muscles. They do not have the balance in the chair that a Class II or Class III individual would have. The Class III individual has good trunk balance and is generally more capable. On a team, Class I's are counted as one point, Class II's as two points and Class III's as three points. To equalize the competition among teams, at no time can a team have on the floor more than twelve points or more than three Class III's. NCAA rules are followed except for a few modifications: In regular basketball you are allowed three seconds in the key; in wheelchair basketball you are allowed five seconds (it takes more time to move with that chair but not a lot more, as you have probably seen). Dribbling is also modified: You are allowed two pushes, then you may pass, shoot, or bounce the ball before pushing again. If you take three pushes, that constitutes traveling. I hope I have given you the basic idea of wheelchair basketball—the first competitive team sport for those confined to wheelchairs.

The National Wheelchair Basketball Association is for males. You see now the advent of women's wheelchair basketball—it has been very slow in getting started. This past year the University of Illinois held its third annual women's wheelchair basketball tournament. There are about five or six teams in existence.

I think it would be a good idea if women adopted a smaller than regulation size basketball, because women generally have smaller hands than men. If women—and here I mean able-bodied players as well as wheelchair players—would adopt what is called the junior ball, which is slightly smaller than a regulation basketball, I think we would see a much classier game. The women would have an easier time handling the ball. You see so many guys who can palm a basketball—pick it up with one hand. But how many women can do that? People with bigger hands can do much more with that basketball. I wrote an article for *Sports 'N Spokes,* a wheelchair sports magazine, suggesting that women adopt the junior ball, and I got so many negative responses: "Oh, we don't want to be put down," "We want to be just like anybody else," and "We don't want that much adaptation." Using a junior ball is not as costly as lowering the basket, which is another suggested adaption. (The regulation basket height is 10 feet.)

My expertise is mainly in what we call wheelchair sports. Sir Ludwig Guttman started the International Stoke-Mandeville Games back in 1948, at about the same time that wheelchair basketball was starting in this country. He started the games at the Stoke-Mandeville Spinal Cord Centre in England, with three countries competing. The United States did not compete until 1960. The First National Wheelchair Games occurred in 1957 at Hofstra University, right here on the East Coast. After that, because of Ben Lipton, the games were held at the Bulova School of Watchmaking and the Bulova factory in Woodside, Long Island. 1960 was the first year that the United States

fielded an international team. The International Stoke-Mandeville Games were held in Rome. Then in 1967 the first Pan American Wheelchair Games were held, in Winnipeg, Canada. I was fortunate enough to compete in them. The Pan American Wheelchair Games differ from the international games in that competition is limited to the countries of North and South America. They are held every other year, in the odd-numbered years.

Prior to 1972, if you wanted to compete in the National Wheelchair Games, all you had to do was get hold of somebody who knew a little about it, get hold of an entry form, and join the National Wheelchair Athletic Association, which is the governing body of the National Wheelchair Games, If you happend to be from the West Coast, you had to raise enough money to get to New York. In 1972 this changed, because so many wheel chair athletes were coming into the picture they could not all be accommodated. So qualifying standards were established, which meant that in order to compete you had to achieve a certain measure of proficiency. For instance, if one of the field events you wanted to enter was throwing the discus, you had to achieve a certain mark to be eligible to compete in the National Wheelchair Games. Now it has become even more stringent, in that in addition to achieving certain standards, you must compete at a sanctioned regional meet. There are now about thirteen sanctioned regional meets in the country. If anybody is interested in where these are, I have a list. Another important event was the formation of the National Wheelchair Officials Association. Prior to this, officiating was very much a hit-or-miss affair; any willing volunteer was enlisted, and it was not always quite fair. But with the advent of the association, a better and fairer competitive aspect has been achieved.

In wheelchair sports, too, a classification system exists, but it is broader than in basketball. In 1967 when I first entered wheelchair sports competitively, there were five classes; now there are seven. The system was designed for leg amputees and those with spinal cord injuries. Classification had become quite controversial. Is it fair for a paraplegic to compete against a spinal cord injured paraplegic? Individuals who have cerebral palsy are very much at a disadvantage because they are generally placed in the least disabled class, Class V, and yet they have coordination problems, which a person with a spinal cord injury does not have. Individuals with osteogenesis imperfecta, which is a brittle bone disease are usually put into Class V because they are able to walk; but they are very much at a disadvantage because they are sometimes very small in stature. Classification is one of the biggest problems, one of the major dilemmas, in wheelchair sports today. Should all disabilities be allowed to compete in the National Wheelchair Games? If so, then changes will have to be made in the classification system.

One of the events in the games is slalom. Another is the obstacle course. One of the field events is the precision javelin. For males the

throwing distance is 33 feet to the center of the target. For females it is 23 feet. You have to throw the javelin at a target on the ground consisting of eight concentric circles. You get six throws and the best five are counted, with a possible total of 80 points. The center of the ring is worth 16 points, and each successive circle from the center drops 2 points. Another field event is the discus throw. The discus used–for both males and females–is the international women's discus. The club throw uses a club that looks like a bowling pin–a very slender wooden thing; this event, which is strictly for quadriplegics is for both distance and precision. The shot-put is another field event. The shot ranges in size for the different classes, from 2 to 4 kilos.

The track events include the dash and distance races. The dash for quadriplegics is 60 yards; 100 yards for all the other classes. In the distance races, the distance for quads is 220 yards. To give you an idea, once around the typical track is 440 yards, so for quads it would be half the distance around the track. For Class II's and Class III's, the distance is 440 yards. There is an 880 yard race for Class IV, which is twice around, and then the mile for Class V. Incidentally, the mile record is held by Randy Wix of Chicago, with a time of 5 minutes, 50 seconds.

An activity that is not in the National Wheelchair Games was started by Bob Hall, a paraplegic. How many of you have heard of Bob? He first entered the Boston Marathon in 1974. Let me tell you some of Bob's accomplishments in marathons. Since 1974 he has entered a number of them. Probably his most outstanding feat was his participation in the Fiesta Marathon in Scottsdale, Arizona; in that marathon–which, incidentally, is 26 miles, 385 yards–he averaged a 6-minute mile, if you can believe that, without stopping. He came in with a time of 2 hours and 30 minutes, a very respectable time. I think there were something like 600 runners, and he came in around tenth. I think that is pretty fantastic, considering that he did it in a wheelchair. In 1977, a National Wheelchair Marathon was held. I do not know all the details for this next year's wheelchair marathon, but competition is by invitation only. What they are attempting to do is make sure that all participants can complete the course. If anybody is interested, I will give you more details later.

Sharon Rahn, from the University of Illinois, also entered the Boston Marathon this past year, along with seven other wheelchair athletes. Bob placed 200 out of 3,016 runners. I think that is fantastic. Sharon was able to do the marathon in 3 hours and 48 minutes, and for a female that is pretty outstanding.

Another wheelchair athlete who is pretty spectacular is Jack Robertson, who, at the time that he attempted to swim the English Channel, was from Arizona. Jack has a spinal cord injury. He did all his training in Cornado, California, because the water there is very similar to conditions in the English Channel. I think the English

Channel is something like 26 miles wide; Jack did 25 miles of that doing the breast stroke—25 miles, without using his legs.

There is also an American Wheelchair Bowling Association. This was founded back in 1962. I do not know a great deal about it. Again, it is mainly male-dominated. I understand that three years ago they allowed women to enter. Last year the first National Wheelchair Softball Association was formed. The first National Wheelchair Softball Tournament was in Sioux Falls, South Dakota. I hail from Yankton, South Dakota, and I was rather surprised to see this. There were four teams: Sioux Falls, the Twin Cities (Minneapolis/St. Paul), Des Moines, Iowa, and Carbondale, Illinois.

This year the National Cerebral Palsy Games are being held for the very first time. Has anybody heard of them? In what city do you think they are being held? None other than Detroit, Michigan. I do not know a great deal about them, but I do have literature to hand out later for anybody who is interested. Most of the events are patterned around the National Wheelchair Athletic Association events, so you will see many of the same events. The classification system I do not understand totally, but those who are interested can pick up an informational sheet.

Another controversial issue in wheelchair sports is wheelchair specifications. Someone stopped me before my talk this evening and asked where I got my wheelchair. It is a Stainless Medical Products wheelchair from southern California. Wheelchairs come in every shape and size. In wheelchair sports, individuals have become very clever at modifying the wheelchair to make it go as fast as it possibly can. I do not know if you have heard of "cambering": You take the back wheels and slant them, so as to get more maneuverability. You put what is called a camber bar on the apex of the crossbar, and you can then adjust the wheels forward, backward, up, down, whatever. Front casters are changing. You rarely see the hard rubber ones now, they are changing to pneumatics. I have pneumatic front casters on my wheelchair. But now a sleeker design has come out that will make a wheelchair go faster. The National Wheelchair Athletic Association, which is the governing body of wheelchair sports, sets up rules governing the competition, including wheelchair specifications: A wheelchair must have push handles; the back must be a certain height; the chair, from the floor to the top of the seat, must be a certain height. Some wheelchair athletes are a bit upset about it. My personal feeling is that the more ingenious an individual is, the more power him or her. Why not? But then again one has to remember that all of this costs money; what about the athletes who can't afford it? Right now a new sports chair costs around $600 to $700, and that is not cheap. And pneumatic tires are about $25 a pair, so adapting also costs quite a lot.

Now I would like to discuss mainstreaming in sports. I taught in two colleges on the West Coast, and I have seen very few disabled college students involved in either sports or physical education. My

personal feeling is that everybody should be involved in physical activity. I think it is very important for an individual. For my part, I feel much better when I am physically active. I have more energy to do other things. One of the reasons I get from diabled college students for not being involved in physical activities is, "I don't have enough time." You would be amazed and probably will not believe me, but if you became involved in physical activity and really were in good shape, you would have much more energy to do your school work. I feel that to have a healthy mind you also have to have a healthy body. The two go together, one is not separate from the other. A club that I recently joined in Las Vegas is called "The Sporting House." It will have an indoor track, and outdoor track, a basketball court, swimming pool, and Nautilus equipment, which is absolutely fantastic. Their philosophy is rather unique, I think, and I would like to share it with you. They say, "Health is a way of life and exercise is the way to living it." And I really think that is true.

As far as mainstreaming in sports is concerned, my personal feeling is that any individual with a physical disability should have the option of taking either a specialized class or a class with able-bodied students. For example, field events–javelin, shot-put, discus–those are individual sports. There is no reason for a special class to be set up. But I think specialization is necessary in team sports, such as football, softball, basketball. I think that it is very hard for an individual in a wheelchair to compete equally with the able-bodied in a team sport unless you devise a "common ground"–everyone plays from a wheelchair.

I do not know if the Easter Seal Telethon was televised nationally. Did people on the East Coast get to see it? Did you happen to catch the wheelchair tennis demonstration? What did you think of Bobby Riggs? I happen to know some of the individuals who were playing against him. Riggs' idea of an even match was to play with a leashed dog in one hand and an umbrella in the other. This was certainly an insult to the two fine wheelchair tennis athletes.

Wheelchair tennis is getting very popular in Los Angeles. Last year the first wheelchair tennis tournament, spearheaded by Jeff Minnebraker, was held in Los Angeles. Very few people turned out for it, which was a pity because it was a lot of fun; I know, I competed in it and I really had a good time. In wheelchair tennis the rules are slightly altered: You are allowed two bounces before hitting the ball, and play is limited to the forecourt. If a wheelchair-bound player is competing against an able-bodied player, the wheelchair bound player plays in the forecourt whereas the able-bodied player plays the full singles court. The able-bodied player must serve underhand.

There is a camp in Georgia that some of you many have heard about. It is called Will-O-Way. It was designed especially for individuals with various disabilities. It is a totally accessible camp located about 60 miles east of Atlanta. You can go fishing if you want to, you can go canoeing; and you can do it all by yourself–you do not need

anybody to check the place out and make sure it is accessible. I really felt free and independent, because if I felt like leaving Atlanta and going up there alone, I could do it. My personal feeling is that every park across the United States should be accessible. Advocates for wilderness areas want the land left in its natural state–which means out of bounds for the wheelchair user. I think we can aim for a happy medium that will allow individuals in wheelchairs or individuals with visual impairments to feel and enjoy the outdoors. I think there is a way to do it.

Let me tell you about a few resources I have. One magazine, which is almost like a bible to me, is called the *Paraplegia News*–a fantastic magazine. Perhaps a lot of you have heard of it. It is put out by the Paralyzed Veterans of America who probably have the most up-to-date information on medical research throughout the world. The magazine is aimed primarily at those with spinal cord injuries. It has a special section on accessibility. It has a section on wheelchair sports. Some of you might be interested in taking a look at this magazine. It is very inexpensive–about $4 for a year's subscription–and is well worth the money.

Something that I received not too long ago is information on the Minnesota Outward Bound program. This year, for the first time, they are starting to involve the physically disabled in Outward Bound. They are going to have two courses this summer, one in June and the other in August. If anybody is interested, I have the information up here.

I also have the National Wheelchair Basketball Association's rules. These I cannot give away, but if you are interested in getting information you can write down the association's address; they would be happy to send you a copy.

There are olympics for the blind. I have little knowledge regarding these, but I do have a copy of a publication that may provide you with more information regarding the olympics and also about sports for the blind.

Olympics also exist for the deaf. They are held every four years. A few years ago, they were held in Yugoslavia. A teaching assistant at Eastern Washington State College, where I taught, had competed in them, on the volleyball team.

A newsletter that you can get free is from the President's Council on Physical Fitness and Sports. The clinics sponsored by the council (I spoke at the one in Portland, Oregon) address primarily the able-bodied. Unfortunately, the physically disabled have not attended. The President's Committee on Physical Fitness in general has not addressed the issue of physical disability. My personal feeling is that we need to let the council know that we are interested in physical fitness.

And this is *Sports 'N Spokes*, which I mentioned earlier. It is a bimonthly magazine that talks about all types of wheelchair sporting activities. The California Wheelchair Athletic Association puts out a newsletter, but you have to join the association to get it. The National

Wheelchair Athletic Association also puts out a newsletter. I have information regarding that.

Lastly, I would like to share with you a dream I have had for a number of years—a dream about a wheelchair sports center. I came quite close to it when I worked for the King County Department of Parks and Recreation in Seattle, Washington. The director of the department at that time was negotiating for a plot of land. I had a group of architecture students from the University of Washington working on the design of a wheelchair sports center, and we came up with a $3 million project that would take up 15 acres. It was really exciting. Unfortunately, for all sorts of political reasons, a lot of individuals were dragging their feet; and I was offered a teaching position at Eastern Washington State College, so I could not stay in Seattle long enough to see it happen.

I have never before had the chance to talk to a group of college students with physical disabilities, and I hope you will share whatever feelings you may have about this dream of mine. My ideas include just about every type of sport imaginable—archery, weight lifting, tennis, swimming, football. I also want to have a small lake so that we can try all sorts of water activities: canoeing, sailing, scuba diving. I want to have a training program for those athletes who are interested in becoming more proficient in wheelchair sports. I want programs for developing the skills of those who are newly disabled and those who have never been involved in sports. I want to incorporate the competitive aspect as well as an experimental aspect. I think that if you are a dreamer, anything is possible, so I have never given up this dream.

You might be shocked to learn that I water ski. How does a spinal cord injured person water ski? Maybe some of you know. We took a group of physically handicapped people from Seattle on a canoeing trip to Snoqualmie National Forest, and we happened to see somebody on the lake water ski sitting down. That was just wild. We flagged down the boat and explained who we were. We asked if we could try it. They called the device an aquabat. I do not have a picture of it, but I will try to describe it. It is a pair of skis with bars and a seat. The seat is maneuverable and it has lots of flexibility; if you lean this way, your skis go that way. Able-bodied skiers can just hang on to the tow rope and lean this way and turn that way. For one of us, we needed to tie the rope to one of the bars, in the center, and it took about three individuals to help the skier get started—an individual on either side to balance the person on the seat and someone to prop up the skis. The skier hangs onto the bar that is right in front, and with any luck at all is still sitting on the skis when the boat takes off. A good friend of mine—a C-6 or C-7 quad—is a fantastic skier with the aquabat. Another friend of mine, postpolio (he got polio when he was about six years old), had never skied in his life; this was his first experience. He was thrilled that he was able to do it.

I believe that with a little bit of imagination, we could find a way

for people with spinal cord injuries to snow ski. But I have never pursued it because it appears to be costly and a big hassle.

The idea I have uses the same principle as a tricycle. A tricycle has three wheels, right? Well, instead of three wheels, one has three runners, skis, with a kind of steering wheel attached. I have not figured out a way to stop the thing. To get up the hill, the only thing I can think of is a snowmobile.

I understand we are going to have some square dancing now. So anybody who wants to see the materials or ask a question, please come up here while they clear the area for square dancing.

Michael Naranjo is a noted sculptor, from the Santa Clara Pueblo of the Tewa Indians. His work has been presented at the White House and exhibited in numerous museums in the West.

Sculpture

Michael Naranjo

Espinola, New Mexico

I would like to tell you where I am from and a little about my people. I am a Santa Clara Indian from the north central part of New Mexico.

My people are pueblo Indians who farm and do a small amount of hunting in mountains that surround the area they live in. A great many of my pieces are related to the life style of the people there. This particular piece, *Little Rain,* shows the type of dress that they used to have at one time. Now they go down to the department stores and buy their clothes, and they do not think about this any more. The pot was used at one time for carrying water on the head. The next piece is called *The Spirit.* He is a clown connected to various ceremonies in the pueblo, particularly the Taos pueblo where this sculpture is from. The next piece is *The War Dancer.* This particular piece on this end is a buffalo, an animal very important to the pueblo's existence. A lot of the dances that the pueblo performed were in honor of the various animals that they killed, in gratitude for the food they received from the animal or for the hides, which they used for making their teepees. There is a particular dance, called "The Eagle Dance," that uses the feathers of the eagle. It is a sacred bird; the feathers are used to keep evil spirits away, and the medicine man uses them quite a bit.

That gives you an idea of some of the things familiar to my people. My sculptures were inspired by the things that my people did in their everyday life. I will tell you how I go about making these sculptures.

When the idea is firm, when I am able to start the sculpture, I get a piece of wire and create an armature for the beginning of the sculpture. Wax is put on this armature in small pieces, and as that is laid on the armature, it starts taking shape, It is difficult to apply the wax, to push it around at times, especially when it gets cold; so I use an electric pot to keep the wax in. That keeps the wax at room temperature, and it can then be applied very easily because it is pliable at this point.

Once the sculpture is starting to form and take shape, there is a very fine communication between the hand and the mind's eye. I will start seeing the sculpture in my mind, and the feeling in my hands will become very sharp and clear, and my hands will work fast enough to form what I am seeing in my mind's eye. But at other times, when I

am very tired, my hands will not work. My mind gets tired and my hands will not work fast enough to fashion what my mind sees.

When I started creating *The War Dancer* I thought about it for about six months before I went into the studio one day to start actually working on him. It is like having to fight against myself, having to make myself sit down and work. It was a very difficult inner struggle to bring this piece out, to make myself sit down. But as I sat there the whole thing became easier to start. I sat there for maybe twenty or twenty-five hours pretty steadily, and then, feeling very, very tired, about three or four o'clock in the morning, I started getting this very large smile, this grin. Because as I was working, the communication between my hands and the sculpture had arrived at last and suddenly in front of my eyes the excitement was there. After about twenty-five hours of working, I slept for about three or four hours and then got up and started to work again. This went on for several days, and at one point I found myself laughing in the middle of the night, about two or three o'clock in the morning, and it scared me because nobody was around; I started to laugh out loud in inner excitement as the sculpture started to take shape.

After about seven days of working like that, the high state of energy I had been working in for that period of time suddenly came to an end with the completion of the sculpture. Becoming very tired when I finally finished the piece, and very empty, I started wondering at that point if it was the last piece I would ever make.

The War Dancer also is a miniature of a large sculpture I have been working on for five years now. Hopefully it will be finished this year. The sculpture is twelve feet tall; when I stand beside that large sculpture and raise my hand, I can touch the dancer on the hip. The whole idea came out of wanting to do monumental sculpture, something I have not done before. At that time I did not quite realize the amount of work involved. There were days and weeks of running around the platform, trying to plaster the large armature that I had welded. The involvement in making that particular sculpture comes into my thoughts, comes into my dreams. One night I had a dream of working on that sculpture. I was on the staging and stood in front of the figure. I was working on a section of the arm. I looked up and I could see this large sculpture above me and I put my arm out trying to reach it, not quite being able to touch it. Suddenly I was looking out of the giant sculpture's eyes, and as I looked down, I saw myself sitting there. I found I had become the sculpture and started to move my arms. Suddenly I was standing inside the giant twelve-foot tall sculpture and could move my arms. I immediately woke up. The experience was very frightening and overwhelming. I waited for a few more hours but could not go back to sleep again.

Once a sculpture is finished in wax it is taken to the foundry, where it is cast into bronze. The sculptures come in varying editions. *The War Dancer* is twelve; so is *The Spirit; Little Rain* is an edition of

ten. *The Buffalo* is an edition of fifty. To make editions, sculptures like the original, I need a mold. A mold is made by spraying the sculpture with a solution that covers the wax and allows clay to be put on all around the sculpture. When the clay is on, the sculpture is covered with plaster of paris. Separators are put in the plaster of paris so that it can be removed. Once the plaster is removed, the clay is taken off the sculpture. The plaster of paris is then reassembled over the sculpture and where the clay was at one time, a liquid called black tuffy is poured. Once it sets, it becomes a hard rubber that can be cut so that the wax can be removed. Usually the original wax sculpture is destroyed in the process. The plaster, which is the mother mold, is cut and reassembled on the top of the black tuffy. Then hot wax is poured into the void where the wax was originally. The sculpture is then inside the molding, and when it hardens, the entire mold is taken apart, along with all the pieces of black tuffy. The entire mold can be reassembled each time to obtain a new wax, and as many sculptures as I need can be cast by this method. Once the wax sculpture are removed from the mold, I dress them. When the mold comes apart, there are some lines in the sculpture from where the mold fits together. Sometimes the wax does not flow completely into all the areas of the mold, creating air bubbles and air pockets, and these have to be filled and smoothed over. This process makes each sculpture an original.

So, that is the mold-making process, which is really quite an art in itself.

Once the wax sculpture is dressed, it is covered with a ceramic solution. Several coats of this ceramic solution are applied to the sculpture, until it is 2 or 3 inches thick, depending on the piece. Then the sculpture is put in a kiln, and the wax is burned out. This method is often called the "lost wax process." Hot bronze can now be poured into the ceramic mold. When the bronze has cooled, the ceramic solution is chipped off. The bronze is then sandblasted to remove any of the ceramic solution remaining on the sculpture. When it comes out of the ceramic solution the bronze looks very shiny, like a new penny. Then the sculpture is covered with liver of sulfur, which gives it the dark color. You can get varying shades with this, and that is called the patina. Once that has been done, the sculpture is ready to be shown to the public.

Let me tell you a little bit about the larger sculpture here. This sculpture is called *The Spirit*, and he is what they call a *che-bo-neh-te*, a clown, who comes into the pueblo twice a year. He is very mischievous when he comes around; he can do whatever he wants, and no one can tell him what to do. I tried to catch this air of mischievousness about him. He says "I am God today, and no one can tell me what I can and what I cannot do." He goes into homes on feast days, wandering around and taunting people, teasing people, and playing in his own way. Children are very afraid of him, and mothers use him as a disciplinarian; they tell their children, "If you don't behave the

che-bo-neh-te will come and get you." When he gets the children he throws them into the river. There is a stream running through the center of Taos pueblo, and quite often on the feast day there, on September 30, you will see a clown—maybe two clowns—with a child under his arm and you will see a mother hanging onto the feet of the child, and the clown will be pulling toward the river and the mother will be pulling back on the child. The clown then goes into the river along with mother and child. I tried with this sculpture to capture this feeling that he carries about him.

Something else very important about the creation of a sculpture is trying to make it work from 360 degrees. It has to work from all sides, as with *The War Dancer*—to get the eye movement, so that when you look at the piece of sculpture, it carries your eyes completely around. What I was trying to do was to get eye movement by turning his head in one direction and having his hands down below with thongs and a flute in each hand, in a different direction; also with the bustles and the straps on the legs, along with the bells. This very important sculpture is a working piece, in that it helps carry your eyes around the entire figure to make it work.

In *The Spirit,* the larger sculpture, the hands are extended. It is difficult to carry across in the sculpture, because when someone lifts his arm up and points, you look at that person and your immediate reaction is to follow his hand, his finger, to see where he is pointing; this takes energy away from the sculpture. I wanted to keep energy within the sculpture, to try to keep it moving, so that the eye would not leave the sculpture but rather be carried around in a flow. To do that, I made the fingers droop, so that the eye movement is not lost, the energy of the sculpture is not lost—it is maintained and kept by the drooping fingers and by the corn husks on the top of the head. The corn husks break up the movement of the face turning, because there is something up there happening other than just the face moving. The corn husks catch the eye and keep the energy within the sculpture there.

One of the reasons I chose this particular sculpture, *The War Dancer,* to raise in scale to a height of twelve feet is because of the movement of the whole piece. It works from all angles; when you look at it things are happening all the way around the piece. When you look at a sculpture, try to get the sculpture to tell you what is happening without anything else, without any other information, without having to be told what the sculpture is doing, what it is, what it means. This is a working piece of sculpture that tells its own story. A sculpture should be made so it can tell its own story, so someone does not always have to be there to tell you what it is all about.

Another sculpture that I did is called *Hoop Dancer*—this man is an Indian dancer jumping through a hoop. You look at the sculpture and you can immediately tell what he is. He is very finely balanced on one foot, showing his skills as he goes through a hoop.

Some of the other sculptures that I have created are a sculpture of St. Peter on the deck of his boat, working on his nets; there is a sculpture of a centaur and one of a mother bear with her two cubs, playing, the two cubs are playing and fighting, and the mother bear is turning around and swinging at the two cubs with her paw. I call that sculpture *The Generation Gap.* They all represent something that I have seen in the past or something that my mind's eye can grasp when I get an idea.

One thing that I particularly enjoyed working on was a sculpture of a pregnant woman. A friend was seven months pregnant and she would come to model. When she first came, her abdomen was large. And as the weeks progressed, the area that I had to keep working on was her abdomen, because her baby continued to grow. It was truly interesting because of the feelings that she was telling me about, and as the time came for her to have her child, I really was able to get an idea of her emotions, the fears within her, of what she thought and felt. I could get a better understanding of the sculpture that I was creating; I could project more of her into the sculpture. I think that this is an important and very necessary part of a sculpture, to get a feeling that it has a personality–there is feeling and emotion in these pieces of sculpture. The birth of a sculpture is analagous to the birth of a child. She, the baby, was born when the time came. And this is the same way these sculptures sometimes evolve; because once the idea is there and has had time to set and form, it becomes very, very strong, and there is not too much that I can do to stop it from happening. I have to sit down and I have to work and the sculpture is created; it is suddenly born. I often connect stories of the past to these sculptures, bring them from yesterday up to the moment when I captured them. Once my sister came in and saw this particular sculpture that I was working on. A week later she came in and asked, "Where is *The Wolf Scout*?" And I told her he had gone on a raid and would be back next week. I really get immersed in the piece of work itself, so that it has feeling and life, somewhere, somehow.

PANEL DISCUSSION

Panelists: Eddie Johnson, Jersey City State College
Elizabeth McKee, Rehabilitation International
Kenneth Phillips, New York Association for the Blind
Harold Snider, Smithsonian Institute

Moderator: Paula Westbrook, Ramapo College

MS. MCKEE: I am hopeful that over the next five years there will be more accessibility as a result of the work I am doing, a chance for more people to move around the country and have the opportunity to meet with artists. I recently returned from the Far East, and they

have programs in several countries; they regard their arts as living treasures, and they provide support for such endeavors.

Part of our program at Rehabilitation International is to develop accessibility for disabled people to travel from abroad to the United States and also to enable the disabled people in the United States to have greater access to travel. Our aim is not just general touring, but making it possible for people to get out to see and participate in various leisure and recreational activities, to become more involved in the creative arts–through study programs, through the visits of artists. I hope that during the question period, there will be specific questions on travel. I certainly do not have all the answers, but I am working hard to achieve greater accessibility in transportation and accommodations so that we can promote the movement of disabled people.

MR. PHILLIPS: I am especially happy to be here today, Michael. I got out of the service in 1965–the Air Force–began a relationship with many disability groups at New York University and took up my first directorship working in a psychiatric hospital. I can identify with what you have been talking about, as we get caught up in "future shock"; in your descriptions and your sensitivity you have today, in your own way, conquered our society and technology–the tremendous input, the changes that are taking place–and have come back to the simplicity of what life is all about.

My only talent–if you can describe it that way–is a deep concern that we begin opening more doors to enable people to express what you have so adequately expressed today. I am very excited about the things we are doing at the Lighthouse. We have opened doors for people who express themselves as you do, through sculpture. I have with me today another resource person, whom I would like to introduce. George Bennett was formerly director of the Lighthouse music school at the New York Association for the Blind (NYAB); he is responsible for the music school but was promoted two years ago to be director of Arts and Leisure Education at NYAB. George is a concert pianist; he went to college in North Carolina and is a graduate of Juilliard. He has greatly stimulated the students, of which there are over four hundred, in the music school and the Adult Leisure Education Program. You may have seen the pictures of the NYAB Arts Festival last year which was a culmination of all the various classes throughout the year. The pictures provide some idea of the various artistic media–stoneware, macrame, needlework, etc. All the artists are either partially sighted or totally blind.

I am very happy and excited to be here with you at this kind of conference where we can exchange ideas. George and I will both be glad to respond to any of your questions.

MR. JOHNSON: Michael, I would like to give very special thanks to you for the feelings you inspired in me as I sat listening to you. I would

also like to offer very special thanks to the lecture series coordinators, Carolyn Scott and Leonard Huber, and many, many thanks to George Smith of Jersey City State College. I am a student there through Telecollege, a service to homebound students through amplified telephone hookups. If I had not met George Smith I would not be sitting here today.

Michael, I was watching you feeling your work, touching your work; I admire that very much, and I was feeling the vibrations from you to me. I do not really know how to do many things well but I have something that I do very well—and that is tricks in my wheelchair. And I like to meet different people—all types of people because I need people, I have that "urge to merge" with people.

I would just like to, if I may, demonstrate my skill, which I acquired from people forcing me to do it. I am thirty years old, and I walked for twenty years, so I know what it is like to walk; and I have been in a wheelchair for ten years, so I know what it is like being in a wheelchair. I say people force me into doing the things I can do now, but I appreciate that because I know now that if I do not make things happen, they will not happen. I used to wait for other people to send me things or do things for me, and this is all I would do, wait. When I am doing these wheelies, a lot of people look at me and think I am playing a game; but it is not a game to me. I used to have to go all the way down the street to a driveway to get off the curb, and then I would have to go all the way back to where I had to cross the street, and I got very tired of that. But once I had learned to balance I did not have to do that. Now I have perfected it. Every roll, when I turn, I can feel inside, and play in that roll if I want to. I have been in a wheelchair for ten years, and the more I do it the better I get. Anything that you do, the more you practice the better you get at it. And so I am doing very well. Also, when I am doing these wheelies people come up to me, approach me in many different ways. Some people tell me that they admire me for their own personal reasons, and that has made me see that I am helping other people as much as I am helping myself.

QUESTION: I have a mild case of cerebral palsy and I find sitting in cramped airplane seats very, very painful. The only areas where you have enough room are the exit areas, and if the airline staff learn that you have any type of handicap they will not put you there because supposedly you are not capable of getting out fast enough. But on the other hand, only once in a while am I forced to use crutches; I appear very normal, and I find that this is a real problem. I usually travel charter to Europe. I am still a student and I do not need to tell you that it is important to be able to travel charter. Is anything being done to overcome the inertia, so that a person who has a handicap will be able to travel a little bit more comfortably on these planes?

MS. MCKEE: I too have problems that are not visible. I requested a

bulkhead seat last Monday on a flight from London to New York, and when I went up to the counter to get my boarding pass I said, "Is this a bulkhead seat?" and I was told, "No, they're only for handicapped people, you can't have one." Basically, there is no regulation that says you cannot have a bulkhead seat. This is one of the problems within the airline industry; every airline has its own policy. The policy has been written at top level and often never gets down to the person at the counter or the cabin crew or the office staff. We have tried; we have been having meetings since last spring with a committee that is made up of major U.S. Airlines and foreign airlines. What we are trying to do is evolve a general policy for handling the handicapped. As you all probably know, some regulations were passed last May which said that every airline must have a policy and must publish it–put it out on the counter where people can see it or make it known to the handicapped in some way. Various airlines have been conferring–their association is called the American Air Transport Association–but not all airlines belong to that. They have been arguing for nine months over establishing a standardized policy. So we have become involved, and we are trying to talk to them from the standpoint of the rehabilitation community. Possibly some of you people are helping through the associations you belong to.

The first thing the aircraft people say to me is, "Please define disabilities." They want it in concrete terms. They know more or less what to expect when they see a person in a wheelchair; but there are great variations in what people who use crutches can do. We have to come up with some sort of classification before we can start doing service training on their personnel.

As far as charters go, there is very little that can be done to make them more comfortable. In fact, the charter business is getting such competition today from the low air fares, that it is creating travel complications. It is a type of travel that will probably be phasing out within a very short period of time. On charters the seats have less padding; if it is uncomfortable for you to sit in a hard seat, then you just have to take an air cushion or some sort of cushion along with you.

We have talked to airlines, we are talking to airlines now, about the planes they are ordering for delivery in 1980 and 1982, trying to get them to make innovations, such as making the seat arm movable so that it will flip up and enable you to transfer more easily into the seat.

We have been working with several engineers in the design of a new type of aisle chair to go into the aircraft. We have talked to people in the aircraft industry about the possibility that the wheelchair itself could be tied down in the plane, rather than the person having to transfer at all. (We have not gone as far with this as we have with the railroad industry.) However, the cost of building an aircraft today is $10,000 a square foot, and American airlines are very, very competitive. They have no government support, as foreign airlines do, so they are interested in getting in as many passenger seats as they can.

I am very sorry to say that it is just a matter of dollars and cents; you are never going to get what is due. We may be able to get them to provide extra pillows and things. One thing I have always advised people in wheelchairs to do; if you are going on a long flight—even first class—and you normally use an air cushion in your wheelchair, for heaven's sake do not let them put it in baggage; take it along with you and use it on your aircraft seat.

QUESTION: My biggest problem is the cramping within the aircraft itself, because I have trouble with my knees.

MS. MCKEE: Then you just have to demand a bulkhead seat. And they are available. When you are booking, just say, "I must have this." There is absolutely no reason to deny it to you. Most airlines do have a policy of using the bulkhead seats for handicapped people—if doing so does not present any safety hazards—because it is easier to get them in and out of that area. In fact, a study was done about a year and a half ago by the Civil Aeronautics Board, and the results were a little bit embarrassing to them. They were expecting it to be more difficult for handicapped people to get off a normal passenger aircraft; but they found that handicapped people, especially those in wheelchairs, were getting out within a second or two of the other passengers. And the blind passengers were able to exit the aircraft just as quickly as the "normal" passengers.

QUESTION: What about the restrooms, especially on long flights?

MS. MCKEE: That has been one of our greatest problems. Even the general public complains that the airlines do not do anything. We have come up with four suggestions to various aircraft manufacturers, all on the enlargement of one restroom, especially on the 747's. One of the suggestions we have offered that is not too terribly costly is to provide one restroom with a door that opens out, and also that there should be a curtain or a screen that will pull down, just as a movie screen pulls down, to give people privacy when they are using the restroom. This is where the cost factor comes in. We talked with two of the major aircraft manufacturers, asking them to put in, as an option, a larger toilet in the rear of the 747. There is one a little bit larger than all the rest back there, and it is usually kept locked because the crew members use it. We are trying to get them to enlarge that one a little more and put the screen device in front of it, so that it can be used by people in wheelchairs comfortably and with privacy. Whether we will get this or not I do not know, but we will keep at it. We continue to discuss it and we continue to get people to write to them about it. It might be in either the 1980 or the 1982 designs. But again, it is a matter of economics.

One of the things they keep saying, is "How many people in wheelchairs are going to use our transatlantic flights? Are we going to have

twenty-five people a year? Fifty? A hundred? Would the number of people we are going to get justify spending $100,000 to $200,000? So we are hoping to develop statistical data on the number of potential customers in the United States. No one has ever done this. It is one of the big studies I have tried to undertake. We have had to narrow it down to one part of the country; there, we are surveying the entire disabled population as to their travel preferences and travel needs, so that we can come back to the aircraft manufacturers and say, "During the next two years you have a potential of X number of customers, X number might be in wheelchairs, therefore, what can you do to make life more comfortable for them on a seven-hour flight?" The people in the airlines' marketing division tell me that if we start gathering some good hard data in every major foreign hotel then we can go to top airline management and say, "There is a real need to make some changes."

QUESTION: I am from a community college. We plan to have a seminar for the visually handicapped this summer, for students who are planning to go to college and have never had the college experience. I was wondering if any of the panel members had any ideas about recreational activities that might help in the socialization of these students who are entering into a new situation, in terms of getting around a college, in terms of having to deal with a lot of different people in a different kind of atmosphere? Are there any new recreational activities that might encourage the socialization?

MR. PHILLIPS: To answer the question very simply, I think the most important thing is what happens between you and the person next to you—what the two of you do in terms of normal conversation or socialization. Recreation, as I see it, is something that has individual interpretations. What is leisure all about? For Michael, it is his sculpture that is his recreation. For you it would be different. For me, it is coming home and joining my son in the Little League and having some fun with my children. I think meeting a person face to face is the beginning. Once you have learned the other person's likes and dislikes, the conversation itself takes on the flavor of interest. If you like to go skiing you will pick partners who are interested in skiing. I think that it has to be somewhat planned, but people are more comfortable having it spontaneous. I think mutual understanding comes first; needs are secondary. Once there is mutual understanding, links begin to form. Then you kind of work yourself into activities. As far as any particular activity is concerned, we have facilities for just about anything you might want to pursue. We have the resources to help people get involved in a variety of community programs. For anyone in New York who is interested, we would be happy to make arrangements for you to attend one of our seminars.

Appendix A Lecturers

Dr. Frank Bowe is director of the American Coalition of Citizens with Disabilities, a consumer-based organization which has as its primary goal, the enhancement of basic human and civil rights of all disabled Americans.

He has been a research scientist at New York University and a teacher of multiply disabled children. His professional activities in 1977 include the Consumer Task Force, White House Conference on Handicapped Individuals and the Committee on Science and Technology, U.S. House of Representatives, Panel on Research Programs to Aid the Handicapped. He is the author of many books and articles on disability.

Dr. Bowe received his Ph.D. from New York University in 1976, specializing in Educational Psychology.

Dr. Frank Bowe
Director
American Coalition of Citizens with Disabilities
Washington, D.C. 20036

Mr. Curtis Brewer is the founder of Untapped Resources, Inc. the only constituted law office in the country which addresses itself exclusively to the legal problems of the physically handicapped.

Mr. Brewer is an advisor to the Architectural and Transportation Barriers Compliance Board and a member of the Board of Directors of the National Center for Law and the Handicapped. He was the recipient of the Thurgood Marshall Award of the New York Trial Lawyer's Association in 1972 and of the Humanitarian Award of the Handicapped Children in 1976. In addition, he has published many articles on the subject of disabilities.

He received his J.D. from Brooklyn Law School and was admitted to the bar in 1974.

Mr. Curtis Brewer
Director
Untapped Resources, Inc.
New York, New York 10009

Dr. Margaret Chanin is Director of Oral Disease Control at Meharry Medical College in Nashville, Tennessee, where she is also Assistant Professor of Preventive Dentistry and Community Health.

Dr. Chanin, a civic leader, serving handicapped children and young adults for many years, has served on the Board of Directors of Outlook Nashville since 1972 and Committee to the Mayor on Employment of the Handicapped since 1976.

Dr. Chanin was a delegate to the White House Conference for the Handicapped in 1977. She received the distinctive honor of Handicapped Professional Woman of the Year in 1970, a joint presentation by the President's Committee and Pilot Club International.

Dr. Chanin received her B.S. From Baylor University, her D.D.S. from the University of Texas, and her M.P.H. from the University of Texas.

Dr. Margaret Chanin
Director
Oral Disease Control Clinic
Meharry Medical College
Nashville, Tennessee 37208

Dr. John J. Gavin currently holds the position of Director of Allergy Research Affairs at Miles Laboratories in Elkhart, Indiana.

He is responsible for the inception of the American Association for the Advancement of Science Project on the Handicapped in Science. He is an active member of the American Coalition of Citizens with Disabilities, and the Indiana Rehabilitation Services Advisory Board for the Deaf. He received the Sidney S. Kramer Award for Meritorious Service to the Handicapped of the Indiana Rehabilitation Service Administration. He has authored scientific publications, holds three patents, and is duly recognized in *American Men and Women in Science.*

Dr. Gavin received his Ph.D. from Rutgers University.

Dr. John Gavin
Director
Allergy Research Affairs
Miles Laboratories
Elkhart, Indiana 46514

Ms. Judith Heumann is senior deputy director of the Center for Independent Living in Berkeley, California, which provides service to disabled citizens integrating them fully into the community. She is also the founder of Disabled In Action, a major advocacy group directed by people with disabilities.

Ms. Heumann is vice-president of the American Coalition of Citizens with Disabilities, chairwoman of the California Coalition of Citizens with Disabilities, and a member of the Rehabilitation Advisory Committee of California. She was a delegate to both the National Conference on Women and the White House Conference on Handicapped Individuals.

She is a graduate of Long Island University and the University of California at Berkeley.

Ms. Judith Heumann
Deputy Director
Center for Independent Living
Berkely, California 94704

Ms. Georgia L. McMurray was the first Commissioner of the Agency for Child Development, an integral part of New York City's Human Resources Administration. In this organization, she was appointed the director of the Social Services Planning of the Special Projects Unit, as well as of the Committee for the Education of Pregnant School Age Girls, and Project Teen Aid.

In addition to the above, Ms. McMurray has since 1976 been the director of the Department of Public Affairs of the Community Services Society of New York. She is vice-president of the Public Education Association and the New Harlem Y.W.C.A. She is also co-founder and chairwoman of the Non-White Caucus.

Ms. McMurray received her Masters in Social Services from Bryn Mawr College.

Ms. Georgia McMurray
Director, Public Relations
Community Service Society
New York, New York 10010

Mr. Michael Naranjo is a noted sculptor from the Santa Clara Pueblo of the Tewa Indians. In 1971, he presented his sculpture, *Dance of the Eagles* to President Nixon at the White House. In 1973, Mr. Naranjo's *Taos Hoop Dancer* won a silver medal at the Scottsdale National Indian Arts Exhibition. In 1974, his *Flight to Freedom* received the First Award as well as the P. Tarmigan Sage Company Grand Award.

Mr. Naranjo's art continues to be displayed at the Head Museum and the Museum of the Horse, both located in Phoenix. It is also on display in numerous private collections and was given a special showing at the Library of Congress and St. John's College in Santa Fe. Recently, examples of his work were included in a collection of Southwestern art selected for Vice-President Mondale.

Mr. Michael Naranjo
Espinola, New Mexico 87532

Dr. Robert Russell, former chairman of the English Department at Franklin and Marshall College, is currently Charles A Dana Professor of English. (He received his Bachelor of Literature from Oxford University in 1951.)

He has been an advisor to the Library of Congress American Council of the Blind Library Committee, and a member of the Pennsylvania Advisory Council on Library Services to the Blind and Physically Handicapped.

Dr. Russell has published numerous articles and essays. He is the author of three books, *To Catch an Angel* (1962), *An Act of Loving* (1967), and *The Island* (1973), all published by Vanguard Press, and the co-author with Gerald Escoe of *The Disciplined Imagination: An Approach to the Reading of Fiction* (Cummings, California, 1969).

Dr. Robert Russell
Franklin and Marshall College
Lancaster, Pennsylvania 17604

Ms. Mariann Soulek, educator and recreation leader, has taught at San Diego State University and Eastern Washington State University. She is currently first vice-president of the Nevada Association of the Physically Handicapped. Her many awards include the Jack Gerhardt Athlete of the Year Award, and the Washington State Handicapped Woman of the Year Award. In 1970, the Mariann Soulek Award was established by the Washington State Wheelchair Games Committee. It is to be presented annually to the female competitor who displays outstanding and continued determination.

Ms. Mariann Soulek
City of Las Vegas
Las Vegas, Nevada 89121

Dr. Harold Yuker is Provost and Dean of Faculties at Hofstra University and Professor and Director of Graduate Programs in Psychology.

Dr. Yuker has served as both treasurer and president of the Nassau County Psychological Association and president of the Social Psychological Division of the New York State Psychological Association. He is a member of the Advisory Board of *College Student Personnel Abstracts* and a consulting editor of *Rehabilitation Psychology*. He is the author of eighty research reports, articles, monographs and the book, *A Guide to Statistical Calculations*, 1958.

Dr. Harold Yuker
Provost and Dean of Faculties
Hofstra University
Hempstead, New York 11550

Appendix B Participants

Yvette Aarons	Long Island University, Brooklyn, N.Y. 11201
Lawrence Allison	Mayor's Office for the Handicapped, New York, N.Y. 10017
Adrienne Asch	Teachers College, New York, N.Y. 10027
Myra Ann Bachman	C. W. Post College, Greenvale, N.Y. 11548
Armand Bakalian	In Touch Networks, Inc., New York, N.Y. 10036
Randi Baker	Baruch College, New York, N.Y. 10010
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